‘Through the patient’s eyes’: shadowing patients at the end of life

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ABSTRACT

Background

The priority given to patient-centred care in recent years has included a requirement for healthcare organisations to collect patient experience data, and to improve patients' experience of care. Shadowing is an experiential technique intended to enable healthcare staff to collect information in a way which will aid them to understand the experience of care from the patient's perspective. It has been introduced recently to quality improvement projects, but accounts of healthcare staff who undertake shadowing have not hitherto been explored.

Aim

To explore the experience for healthcare staff of shadowing their patients and their motivation to make improvements.

Method

An exploratory qualitative study with a diverse sample of 20 clinical and non-clinical healthcare staff in different end of life settings, including acute hospitals, community and mental health, and care and nursing homes. Data were analysed using Thematic Analysis (Braun and Clarke, 2006).

Results

Participants' accounts of shadowing revealed that their initial anxieties about aspects of shadowing did not materialise, although for some it was an 'unusual' experience, placing them in a novel relationship with patients. For some participants, shadowing had a powerful personal impact, intensified by being with patients who were at end of life. Shadowing promoted better insights into the experience of patients and their families, thus motivating participants to focus their improvement efforts. However, most participants were unaware that they were bringing their personal and professional lens to what they observed, which may influence their interpretation of the patients' experience.

Conclusion

The challenge to taking up shadowing is not primarily logistical but emotional. Healthcare staff need to be supported to be aware of how shadowing may affect them. It may involve the need to manage their emotion, and to be reflexive so that appropriate service changes are made for patients and families.

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AUTHOR'S DECLARATION

I declare that all the material contained in this thesis is my own work.

CHAPTER 1: INTRODUCTION

1.1. Background

There has been a drive in recent years to improve patient-centred care (Institute of Medicine, 2001; Goodrich and Cornwell, 2002) with patient experience now recognised as an essential component of quality in healthcare (Darzi, 2008). The relationship between elements of patient-centred care and improved experience has been established for some time (Stewart, 1995; Luxford et al., 2010; Howick et al., 2018). Quality improvement initiatives in healthcare are widespread across the health service, and the participants in this study were taking part in a programme, 'Living Well to the Very End' (henceforth referred to as Living Well) to improve the experience of care in end of life services. It is known that service improvement approaches introduced to the NHS in recent years have not all been acceptable or popular with staff (Gleeson et al., 2016), and quality improvement projects can have a negative association with worker satisfaction (Dixon-Woods, 2016). However, why this might be, and corresponding investigation of the experience of staff who take part in healthcare quality improvement initiatives is an under-researched area. Likewise, understanding what engages and motivates healthcare staff to make quality improvements, and how to appeal to their intrinsic motivation, is an area of interest in quality improvement research (Dixon-Woods et al., 2014). This study explores, through accounts of those who took part in the Living Well programme, how they felt about it, and the barriers and challenges. The study looks at the impact on staff and their attitudes and behaviours, which have hitherto not been documented in depth (Robert et al.,2015).

The premise of the Living Well programme was that there is a need to understand how patients experience a service, in order to improve that experience. The second premise of the programme is that experiential approaches to collecting information, such as patient shadowing, will enable a better understanding of the immediate experience of care 'through the patient's eyes' (Delbanco, 1996) and thus make service improvements that will target what is important to patients and their families. The experiential approach the participants were required to undertake was patient shadowing, an approach which involves accompanying patients as they receive care, which has been highlighted as potentially having a valuable role in advancing patient centred care Liberati 2015, p.2). The detail of the process of shadowing has not been documented before, a failing of quality improvement literature in general (Dixon- Woods, 2016), and Liberati goes on to say that thorough examination of its practical, methodological and ethical challenges is still lacking, and crucially, how findings from shadowing convert into impacts on patients' care.

In summary, this study addresses these gaps; it explores the impact of shadowing on the shadowers, both on their knowledge and emotions, and on their subsequent actions, and seeks to understand the relationships between these. The study will also aim to illuminate what is involved in practical terms in shadowing patients, and provide guidance for future teams.

Aim

To explore the experience of healthcare staff of shadowing patients (and families)

Objectives

To seek to understand the process and experience of shadowing and its acceptability for staff.

To explore the relationship between shadowing, knowledge, empathy and motivation to make improvements.

To produce practical guidance for future teams.

Participants in the study were members of 19 multidisciplinary healthcare teams from across England who took part in a quality improvement programme led by The Point of Care Foundation (PoCF), a not-for-profit organisation that works to improve the experience of patients and staff in the NHS. The Patient and Family Centred Care (PFCC) programme, first adopted with orthopaedic patients in the USA (DiGioia, Greenhouse and Levison, 2007) has been adapted by the PoCF and taught three times since 2010. This fourth programme focused specifically on quality improvement in end of life care. It is a collaborative learning model and participants attended three learning events in the course of the programme, running from July 2017 to April 2018.

Participants were taught conventional quality improvement (QI) methods, but in addition a key requirement was for healthcare staff to shadow patients (in other words, to accompany them and observe their experience of care) to inform their understanding of where to focus improvement efforts (DiGioia and Greenhouse, 2011). Guidance (both verbal and in a written handbook) was provided beforehand for all shadowers.

1.2. An overview of the thesis

Chapter 2: Research and policy review

The chapter begins with a review of the literature relevant to the study in three categories: research, practice, and theoretical (Aveyard, 2014). It sets out the results of a scoping review of the research and practice literature, which involved a systematic search both of the literature related to improving patient-centred care to enable better patient experience, and of improvement projects which use approaches that enable healthcare staff to understand experience from the patient's point of view. This included a search for accounts of patient shadowing, the technique used by participants who were the focus of this study, which involves accompanying a patient to observe their experience in real time.

The results are analysed in terms of reported outcomes for patients and impact on staff who undertook improvement projects. The discussion briefly draws on the theoretical literature to offer some explanations for why there are challenges for participants undertaking this kind of work. The chapter then examines the policy context for the participants in the study, members of healthcare teams working in the NHS who were taking part in a programme to improve the experience of patients (and their families) at the end of life. The chapter concludes with the gaps this study addresses, which is both the lack of detailed descriptions in the research literature of interventions to improve patient experience, particularly experiential approaches such as shadowing, and the paucity of research which examines the impact for healthcare staff of taking part in such projects.

Chapter 3: Methods

This research uses semi-structured interviews to explore the experience and impact of shadowing patients with a purposive sample of 20 healthcare staff who took part in a collaborative learning programme to improve the experience of care for patients at the end of life. The qualitative data were analysed using Thematic Analysis (TA) (Braun and Clarke 2006; Braun and Clarke, 2013). A short quantitative survey was administered to all the programme participants at the start and end of the programme. This chapter has seven sections: the first section provides an overview of the setting, aims and objectives of the study in order to put the rest of the chapter in context. The second section describes the study design and rationale for a mixed methods, predominantly qualitative approach; the third section discusses the researcher's assumptions in relation to the study; the fourth section describes ethical issues; the fifth section describes the sampling approach, recruitment and data collection and recruitment; the sixth outlines the particular method of data analysis (TA) for the qualitative data, and the seventh, final section, summarises quality assurance.

Chapter 4: observations, attitudes and feelings about 'doing' shadowing – the practical side

Whilst primarily qualitative in focus, a quantitative questionnaire was also utilised to assess changes in knowledge, confidence and empathy pre- and post-shadowing, and findings from this are discussed first. This chapter presents and discusses results that pertain to the activity of shadowing; what the participants observed and how they went about it. It examines how the participants felt about undertaking shadowing before they started, and how this changed as they did the shadowing. Distinct from this, it explores the emotions evoked for the study participants by being with patients in this way, and patients at end of life in particular. Speculation about how those being shadowed might have thought or felt about being observed in this way is included. Finally, the different styles of shadowing adopted by participants are described.

Chapter 5: Responding to the experience of shadowing: how change came about for patients

The second results chapter explores how participants undertook the task of shadowing by adopting different styles. Next, the contribution shadowing might make to patient centred care, through the impact shadowing had on participants, and how in turn their response to the experience could bring about change for patients is explored. ‘Work as imagined and work as done’ is a familiar concept in quality improvement projects which focus on patient safety, and changes in knowledge and understanding of patient experience are demonstrated. The emotional response, and affective empathy are discussed next, which relates to how observations are necessarily subjective for different reasons. Motivation of participants to make change is included, and lastly the participants’ reflections on how shadowing as an approach might make a difference to service improvement is set out.

Chapter 6: Discussion

The chapter discusses the findings in more depth in relation to the literature. It explores the place of emotion in quality improvement work of this kind, in relation to professional detachment and defences against anxiety, and empathy and emotional response. It explores whether it is possible, or even desirable to ‘see through the patient’s eyes’. How increased understanding of patients’ experience might come about, and motivation to make change are explored. The implications of the study for policy, and recommendations for practice are presented. Finally, a critical reflection on the thesis is included.

CHAPTER 2: RESEARCH AND POLICY REVIEW

2.1. Introduction

The participants in this study were taking part in a programme designed to improve patients' experience of care. This chapter describes what lies behind the concept of 'patient experience'. First, results are presented of a scoping review of the research and practice literature, which aimed to discover how service improvement for patient experience has been attempted so far. In particular, approaches which seek to understand the experience of care from the patient's perspective are reviewed. The impact of these approaches for staff is identified as a gap in the literature and thus highlights the contribution of this study. The discussion briefly draws on the theoretical literature to offer some explanations for why there are challenges for participants undertaking quality improvement work, particularly using an experiential approach.

The second part of the chapter examines the healthcare policy context for the study's participants. It describes how 'patient experience' has been operationalised, defined and measured and how it is now seen as an aspect of quality in healthcare services which needs to be improved.

PART ONE

2.2. Scoping review: aims and methods

The research question for the study was defined broadly at first: to explore the impact on healthcare staff of using quality improvement methods which can help them to understand the experience of patients. The scoping review was conducted in order to inform the study before it started. The review's primary purpose was:

- To explore the literature related to patients' experience in terms of documented interventions which focus on improving patient-centred care
- Within this, to seek literature relevant to improvement efforts which capture the patients' perspective, enabling healthcare staff to see 'through the patients' eyes' (Gerteis, 1993)
- To identify studies which documented demonstrable improvements for patients

- To find studies which examined the experience for staff of taking part in these programmes or projects.

The secondary purpose was to confirm that this study would address gaps in the literature.

2.2.1. Search strategy

Initial scoping of the literature was carried out to help to refine the research question, to make a list of key words for searching, and to develop inclusion and exclusion criteria. This first search was done through the University of Westminster's Library Search database.

Inclusion/exclusion criteria

Literature in English since 2007 was included; this date was chosen as a cut off because of the author's previous review of the literature for the report *Seeing the person in the patient* which was carried out in 2007/8 (Goodrich and Cornwell, 2008). Some earlier papers were followed up if found through citations. Any healthcare settings and patient populations were included. Qualitative and quantitative research studies and any practice or theoretical literature which might shed light on the research question and study design were included. Patient safety (and quality) and clinical effectiveness (and quality) were excluded. Patient involvement in one's own care was excluded.

A more focused search strategy followed, on the same database, designed to identify any existing studies that fitted with the inclusion criteria. Next, five databases were searched separately: Medline, Ethos, CINAHL and Psycinfo, as well as the The King's Fund's library database (part of HMIC). A wide number of search terms and combination of terms was used (see below); it appears that there is an inconsistency in index terms for the literature in the area of both patient experience and in quality improvement (noted by other reviewers (Gleeson et al., 2016)).

Keywords

Patient experience

Patient-centred care, person-centred care, relationship-centred care

Quality improvement, continuous improvement

Patient involvement, involving patients, patient engagement, PPI

Collaboration and patients

Codesign, participatory design, user-led design, human-centred design, user-led innovation, coproduction, co-creation

Shadowing

Patient stories, patient narrative

Empathy

Reflexive learning

Searches using these terms alone and then in combination, using Boolean operators, resulted in a high number of 'false drops' (papers which were not relevant). Adding even more key words was tried, identified by looking at which subject headings were included at the end of useful papers. Terms added later included patient stories; participatory design; user-centred healthcare design; service design; innovation. Papers were quickly scanned (titles and abstracts) and if appeared relevant imported into a named folder in Refworks. Hand-searching was carried out of journals identified as appearing most frequently in searches for the topic areas of patient experience, patient-centred care, and quality improvement. Journals that were hand-searched included *BMJ Quality and Safety* online; *BMC Health Services Research*; *Health Expectations*; *Journal of Patient Experience and Journal of Compassionate Care*, and this yielded additional papers which discussed methods for understanding patient experience incidentally (rather than in the abstracts). A day was spent in a specialist library (the King's Fund) to search through hard copies of journals, and to consult the librarians there about possible grey literature. Meanwhile grey literature was also found on websites, notably The Health Foundation, National Voices, The King's Fund and Nesta. Subscribing to these organisations' current awareness bulletins and scanning them regularly was part of the search strategy. Checking with experts was fruitful: key academics in the field of patient narrative, patient films and experience based codesign, and one author of a PhD thesis found on

Ethos were contacted by email. They suggested papers and book chapters. Professional colleagues were consulted, including a colleague who is a founding member of the Health Foundation's Q initiative (which connects people with improvement expertise across the UK). Greenhalgh and Peacock (2005) refer to 'serendipity' as a valid contribution to literature search strategies, and in this way chance conversations at professional meetings were helpful, yielding suggestions for new research papers or book chapters to check.

The scoping review followed the approach for a systematic search set out in Aveyard (2014), and results were initially organised by randomised and other controlled trials, meta-analyses of qualitative studies, followed by systematic reviews of the literature, other reviews, and primary studies. Four types of literature are usually found in the field of health and social care: policy, research, practice, and theoretical literature (Aveyard, p.44), and the scoping review was organised accordingly. Papers were then added to the Refworks folder, and duplicates removed, bringing the total to 75. These were scanned again and more excluded; the main reason at this stage was that on closer inspection they were not concerned with improving patients' experience.

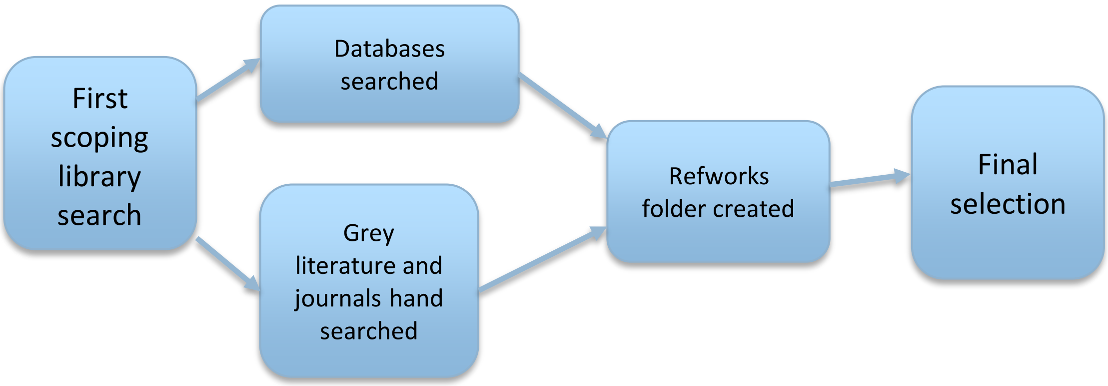

Fig.1. Search method

37 remained and were read in full to see whether the improvement approach was described in enough detail to ascertain whether it was helping healthcare staff to see through their patients eyes (for example, collecting or hearing patients' narratives, observation or shadowing). These were then assessed to see whether impact and outcomes for patients were described, as part of assessing the quality of the papers

more broadly, using the CASP framework[1]. Even if judged poor or flawed using CASP criteria, papers were not excluded (because there are so few) if they still added something of help to the research question, for example, if the description of the intervention or QI method was useful. Funnelling down (fig.2) to papers which included a description of impact or outcomes on staff resulted in so few (ten) that all were kept regardless of research quality. The final number of papers selected was 23. See appendix A, showing details of selected studies.

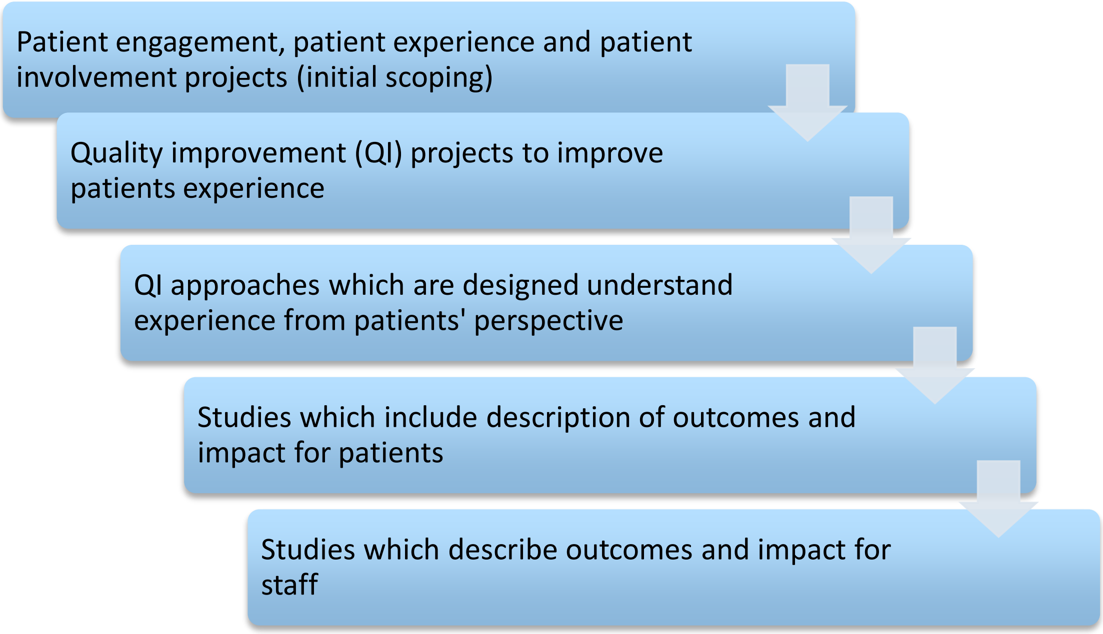

Fig.2. The ‘funnelling’ process

Aspects of the topic of improving patient experience cut across several bodies of literature (including quality improvement, patient experience, ethnography, co-production, and co-design). For example, approaches that place emphasis on the experiential (in this case enabling staff to understand the experience of being a patient) are familiar in the co-design world (Donetto et al., 2015). Innovative work is taking place in the field, and internet searches revealed that small voluntary sector groups are facilitating projects which involve service users, particularly in mental health, in

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[1] www.casp-uk.net

coproducing their services. Designers from disciplines such as engineering, architecture, graphic and interior design are coming together with patients to design solutions to health issues which they have identified together. Examples of academic centres include Sheffield Hallam University's User-Centred Healthcare Design centre[2], and the Helix Centre at Imperial College London [3].

During the course of the study, papers were added to the reference manager database as and when they were found, with the help of regular electronic updates set up through library databases, such as Medline and The King's Fund. The scoping review did not explicitly focus on literature relevant to end of life care, but this was sought as the study progressed and themes related to end of life, death and dying, were becoming more prominent within the qualitative interviews. The concept of 'total pain' was pioneered by Cicely Saunders, the founder of the hospice movement, and refers to the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles (Clark, 1999). There is a large body of literature, mainly in oncology and palliative care related to patients being cared for by specialist palliative teams (for example in hospices, or specialist palliative units in hospitals), and many of these focus on relational care, particularly communication skills (Kissane et al, 2017., 2015; Fallowfield et al., 2002) and emotional and spiritual care (Edwards et al., 2010) However, a systematic search of palliative care literature was not undertaken, because the participants in the study were not palliative care specialists and were not working in palliative settings. They were caring for patients at end of life, in general settings; their patients were generally not registered as palliative. Systematic reviews which focus on the experience of patients at end of life in generalist settings, are less numerous. Nevertheless, it was possible to supplement the initial scoping review with two literature reviews (Brighton and Bristowe, 2016; Virdun et al., 2015) and a small number of relevant papers, including primary studies, after a search of two specialist databases, The King's Fund and Marie Curie library databases. (Robinson et al., 2014; Caswell, 2015;

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[2] https://www.shu.ac.uk/research/specialisms/cultural-communication-and-computing-research-institute/what-we-do/projects/design/user-centred-healthcare-design

[3] https://helixcentre.com/project-advance-care-plans

Rogers, 2000; Borgstrom and Barclay, 2019; Donnelly, 2018; Ó Coimín, 2019; Gott, 2019; Johnson et al, 2019).

2.3. Results

The scoping review uncovered two shortcomings. There is a disappointingly small amount of high quality research literature in the area of improving patient-centred care, and its demonstrable impact on patient experience, confirmed by published reviews. Indeed a previous review found the same lack of rigorous studies for the field of quality improvement more widely (Dixon-Woods, 2016). Many primary studies do not meet recognised quality criteria: most, but not all, set out the aims and objectives of the research, but do not describe the research method in detail, for example how the sample was reached or how data were analysed. Secondly, many evaluation studies do not clearly describe service improvements or experience-related outcomes for patients achieved by the projects. With these caveats in mind, results of the review are presented here.

2.3.1. What is important to patients: patient-centred care and patients' experience.

High quality patient-centred care has been defined as encompassing a number of dimensions (see section 2.5). The Institute of Medicine, for example, provides an internationally recognised definition which includes compassion and empathy; emotional support; information and communication; physical comfort; co-ordination and involvement of family and friends (Institute of Medicine, 2008). Evidence from the results of the scoping review shows that if attention is paid to these aspects of patient-centred care (for example good communication with patients and their relatives) it has a positive impact on reported patient experience. Studies which explore patient-centred care or patient experience demonstrate that 'relational' aspects of care are important to patients, which is often expressed by patients as being seen as an individual, or a whole person, rather than a 'number' or a disease (Sweeney, 2009; Goodrich and Cornwell, 2008). The strongest evidence of the impact of patient-centred care from systematic reviews (and the most frequently studied aspect of patient-centred care) is communication. Poor communication is cited consistently in studies of patients in every setting (Stewart, 1995; Dwamena et al., 2012; Howick et al 2018) including end of life care (McDonald and Sherlock, 2016; Ó Coimín et al., 2019; Virdun et al., 2015) and is the aspect of patient-centredness which appears to have the greatest positive impact on patient experience. It has been demonstrated that healthcare practitioners who enhance how they express empathy and create positive expectations improve patient outcomes; a systematic review and meta-analysis has shown that empathic consultations improved pain, anxiety and satisfaction (Howick et al., 2018). It is not only the style of communication that is important, but the provision of information to patients; for example information provision before surgery can improve post-operative pain and improve recovery (Shuldham, 1999).

Studies of the experience of patients in different settings, including hospital and general practice, and which include narratives from patients, reveal what is important to them. Here the same themes about relational, or 'human' aspects of care reoccur: good communication (both in terms of being provided with information about their condition or processes to expect, and being spoken to with kindness and respect) is a frequent theme, along with being treated with dignity and respect. (Howick, 2018, Dwamena, 2012, Stewart, 1995, Levenson, 2007). These themes are equally important in end of life care (Robinson, 2014). Rogers et al. (1999) analysed the free text responses to a large survey of bereaved carers (whose relative had died in hospital) and found that the greatest cause for dissatisfaction was the way hospital staff communicated with patients, and loss of dignity or 'dehumanisation'. The researchers quote one carer's response to illustrate this: *"All the services were excellent. It is when the human element comes in that things go wrong*". Other key themes include being involved in decisions about their care, continuity and co-ordination of care (for example not having to explain the same thing about themselves repeatedly) (Levenson, 2007; Goodrich and Cornwell, 2008, p.10). In terms of physical comfort, pain relief is an important theme for patients in general (Levenson 2007) and at end of life (Black et al., 2018). It is striking that the same themes are found in different health settings, including mental health and children's health (Springham and Robert, 2015), and in end of life care (Heyland et al., 2006). Of these, the most longstanding research literature appears to be in the area of communication, and this is also a priority for end of life and palliative care, with its concern for the spiritual and emotional care of patients (Fallowfield, 2002; Stewart, 1995; Dwamena et al., 2012). A noteworthy theme beyond these is that patients and families repeatedly mention small things that can make a big difference (for the better) to their experience of care, and that these are what they remember. This is also true in end of life care, and is illustrated by qualitative studies which looks at experiences of good end of life care in hospital (Gott et al., 2019, Sinclair, 2017). For example, a relative described how, after being given bad news about her father, she was taken by the doctor for a cup of tea, and this act of kindness remained with her, helping her during a difficult time (Gott et al., 2019).

Coordination and integration of care is particularly important to patients when they move between healthcare services, or between parts of a hospital (Haggerty et al., 2003). Pain relief is a key aspect of physical comfort, but noise, temperature, food and drink are also important to patients (Care Quality Commission, 2019). Involving family and friends in care is particularly important in certain situations such as end of life care (Harding and Higginson, 2003; Andershed, 2006; Hudson and Aranda, 2014).

Given the caveats referred to above about the quality of the literature, it is nevertheless possible to conclude that projects to improve patient experience in, for example, the doctor-patient consultation, or on wards for frail older patients, or in cancer services, or dementia services, have focused on these common themes of patient-centred care, and have focused accordingly on making improvements in these areas. The published accounts related to improvement efforts have most often been in relation to better communication and information for patients, including end of life patients (Borgstrom and Barclay, 2019).

2.3.2. Quality improvement approaches which capture patients' perspective

A systematic review of the use of patient experience data for quality improvement in healthcare settings, concluded that 'approaches more prominently involving patient voice and co-designed with patients seemed to be the most acceptable [to healthcare staff] although even here evidence of impact was limited' (Gleeson et al., 2016). Papers related to projects which were aiming to improve patient experience and which capture the patients' perspective tended to be in the realm of practice literature (which often overlaps with research literature). This included accounts of participatory action research projects and other evaluations of interventions, often written up as case studies. However, as already stated, published research often does not provide a comprehensive account of the intervention itself, so it is not possible to assess the improvement approach or component parts of an approach (including shadowing). The quality improvement literature has been subject to criticism for this reason (Dixon-Woods, 2016; Dixon-Woods, 2019) and because the evidence is of poor quality it is hard to claim an intervention has been effective. There are some useful exceptions which are written with the intention of describing a method so that others can use it, including the 'Patient and Family Centred Care' project (PFCC), which included patient shadowing as a key component. Many reports in peer reviewed papers do not present outcomes for patients based on clear data, but the PFCC project reported improved patient outcomes: including increased patient satisfaction, reduced infection and reduced length of stay in hospital after knee or hip replacement (Di Gioia, Greenhouse and Levison, 2007; Di Gioia, 2011).

Much relevant literature in the area of service improvement where the patient's voice is prominent is the grey literature, and include 'good practice' examples of projects which might include more detail about the intervention than is found in the academic literature. These were typically found on websites (The King's Fund, The Change Foundation), sometimes as part of an impact or evaluation report, and described in practical terms. For example, The Change Foundation's report on its co-designed improvement projects with patients, family carers and healthcare professionals in Ontario, Canada, described how patients and family carers were recruited and engaged in the projects, how ideas for change to services were generated and whether they were implemented[4].

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[4] https://changefoundation.ca/lessons-changing-care/

Methods which are explicitly designed to reveal the experience of care from the patients' and families' perspective fell broadly into three types in the scoping review: experiential learning; patient narratives; and observation and shadowing.

Experiential learning is an approach to teaching and training in healthcare. It aims to be a process of personal insight development, in which one's own and others' experiences are used to enable change in behaviours (Kolb, 1983). In training and education, experiential learning is used often as part of teaching about empathy (Boodman, 2015). It mainly relates to training student health professionals, using simulation approaches where students experience being a patient through, for example lying in a bed, or spending a day in a wheelchair (ter Beest et al., 2018). Immersive learning has been shown to increase understanding and connection to patients, and 'eye-opening' insights into their experience of living with illness, and empathy (Halton and Cartwright, 2018). In recent years there have been a number of initiatives in the NHS encouraging healthcare staff to put themselves in the place of patients, for example, 'A Mile in My Shoes', and the '15 Steps Challenge' (The Health Foundation, 2016; NHS England, 2017) but published evaluation of sustained outcomes for patients in these programmes could not be found.

Hearing the story of a patient's experience of illness and care received, and what aspects are important to them, with the idea that personal stories will encourage changes in how healthcare services are designed and delivered, has been part of service improvement work in the UK for two decades. The collection of patient stories, or narrative accounts for quality improvement was encouraged by the Modernisation Agency (Wilcock et al., 2003). This approach involved staff engaging with patients to collect stories about their experience of care. These accounts were then read to staff at a general meeting in order to identify how care could be improved. Patients were not involved from then on. The method appears to have been used particularly in older people's care where changes to care have resulted, ranging from small changes to direct patient care, to changes in policy for the whole hospital, though details are not provided (Bridges et al., 2010, Bridges and Nicholson, 2008). More recently, filmed narratives from patients talking about health experiences have come to the fore, for example the

Healthtalk project gathers narratives from patients through qualitative interviews which are also filmed for use in improvement work (http://www.healthtalk.org).

Experience based co-design (EBCD) is a participatory action research approach, which combines the collection and filming of narratives from patients, and observation. EBCD was introduced to healthcare in 2006 by Paul Bate and Glenn Robert, first piloted in the head and neck cancer service at Luton and Dunstable hospital (Bate and Robert, 2007). It was first introduced as a participatory action research method but is now widely acknowledged as an effective quality improvement method (Van Deventer, 2016). Co-design is part of the wider concept of co-production (though is often used interchangeably), which has been common in public services for some decades. A useful definition of co-production is ‘the involvement of public service users in any of the design, management, delivery and/or evaluation of public services’ (Osborne, 2016). Thus the main difference in a healthcare context would be that patients or service users would be involved in some way in delivering a service. This is most common in mental health (Slay and Stephens, 2013). EBCD follows a specific method, or process with clearly defined steps. It is a collaborative approach which ensures that services are designed, or re-designed to meet the needs of service users and staff through their working together at every stage. EBCD has an emphasis on the importance of carrying out observation in the clinical area intended for improvement and it also makes use of patients’ filmed narratives and emotional mapping to identify the ‘touchpoints’ in the patients’ experiences, which will then highlight where improvements should be focused. Staff are also interviewed about their experience of working in the service. Patients and staff work together in small groups over a period of months or longer to create ideas for change, prototype, test and implement the improvements. Patients’ narratives are filmed as part of the EBCD method, and these appear to have a powerful impact on the staff who watch them (Adams et al., 2015).

Changes in services have been achieved using this method and have been well documented in the first and several subsequent projects, for example new appointments systems, communication training for receptionists, new protocol for breaking bad news, a support group for those discharged from the service, information for relatives of those going through chemotherapy. (Piper et al., 2012; Tsianakas, V et al., 2012; Robert et al., 2015). A rapid evidence synthesis (Clarke et al., 2017) of studies using co production observes that outcomes are reported within three categories: staff and patient involvement in the process (seen as an end in itself); generation of ideas and suggestions for changes to services which impact on patients' and carers' experiences (and indirectly on staff's); and actual, tangible changes in services and impact on experiences. In the primary studies of EBCD projects included in this scoping review, outcomes for patients or their carers are occasionally clearly included (Tsianakas, V. et al., 2015; Locock et al., 2014; Boyd et al., 2012; Vennik et al., 2016). Examples include day surgery redesign, carers allowed in surgery waiting area, clinic procedures reviewed and revised to reduce waiting time, V-shaped pillows provided, redesigned appointment letters, surgery dates agreed on day results given, a staff photoboard, improved oral and written information, reception staff training. Published quality improvement projects in end of life care are rare, but EBCD has been shown to have potential to bring about change, for example improved information and communication for end of life patients and their families presenting in the emergency department (Borgstrom, 2019).

Outcomes are usually shown in terms of immediate changes in services, but with one exception found in the grey literature (Adams et al., 2014), do not look at whether changes were sustained over time. Adams et al. (2014) found that 66% of changes had been sustained 19-22 months later, which is a higher proportion than is typical of other QI methods. The authors categorised changes into 'quick fix' solutions which involved little or no change in everyday working practices (for example revisions to written patient information); process redesign within a service (for example, new in-service procedures for patient consent); process and structural redesign which spanned different services (for example, improving access to pre- and post-operative physiotherapy care); and, finally, there were several organisational level solutions (for example, addressing delays in obtaining scan results). They concluded that these four categories were progressively more challenging to implement and sustain, with 24 out of 28 'quick fix' solutions sustained over time.

Observation and shadowing are closely related. Observation as part of an EBCD project would involve sitting still and observing a clinical area, or environment where improvement is planned, without interacting with anyone else. Observation is an important part of the EBCD process but is less often referred to in written accounts of projects. A survey of projects revealed that it was the part of the method that was most often neglected (Donetto, Tsianakas and Robert, 2014). Patient shadowing is a variation on static observation and means accompanying individuals during the course of their daily activities. The person shadowing may join in conversation with the person being shadowed. Shadowing is seen as getting alongside the patient and experiencing the service with them, rather than observing what happens objectively. Both observation and shadowing have been used in health research as a way of seeing clinical care from the patients' point of view, and of studying 'patient-centredness' (Barker et al., 2016; Sloane et al., 2007; van der Meide et al., 2013; van der Meide et al., 2015). Researchers particularly observed the nature of the interactions between staff and patients, such as the way staff communicated with vulnerable patients who were frail or had dementia and whether the member of staff explained what was happening as they cared for the patient. Although a recognised research activity, and seen as having value as a patient-centred method (through capturing things important to patients which may have been missed using other methods) (Liberati, 2016), patient shadowing is not widespread as part of quality improvement. At best, researchers relay their findings to healthcare staff in the hope that improvements would be made, but what shadowers do, and how they convert their findings into impact on patients' care experience is not documented (Liberati, 2016). Shadowing is undertaken occasionally in education and training where student clinicians or management trainees typically shadow other members of staff (rather than patients) in order to understand their roles (Gill, 2013). But it does not appear that shadowing patients is usually considered for improvement purposes, with the exception of a documented systematic programme (the ImERSE programme) for medical students in one healthcare trust, where outcomes documented were changes to the patient waiting area and information provided about pre-medication in day case surgery (Calvert, 2015; Calvert et al., 2018). The only other programme which includes patient shadowing is 'Patient and Family Centred Care'. PFCC was developed from a local project in orthopaedic surgery and has progressed to be described as a quality improvement method (DiGioia and Greenhouse, 2011; DiGioia et al., 2007). This programme was adapted by the Point of Care Foundation and is the focus of this study.

2.3.3. The relationship between staff and patients: outcomes and impact for staff

No studies were found in the scoping review which had a primary focus on the experience, or impact on, the healthcare staff who took part in projects to improve patient experience. A need to change clinician behaviour was identified as important for the success of quality improvement projects (Gleeson et al., 2016), but was found to be a neglected area. Experiential approaches to service improvement (collecting patient narratives, shadowing) put healthcare staff into a relationship with patients which is different from their day to day roles, and it can be assumed that this might have an impact on them. It is therefore surprising that outcomes for staff (for example increase in job satisfaction, or engagement with work) are even more scarcely recorded than for patients. It has been found that other service improvement approaches introduced to the NHS in recent years, focusing on process or efficiency for example, have not been positively received by staff and indeed have a negative association with worker satisfaction (Gleeson et al., 2016; Dixon-Woods, 2016). It is possible that the service improvements focusing on patient-centred care and patient experience which are documented in some projects will also benefit staff. However, there is virtually no explicit work on the personal impact for staff (for example increased QI skills or confidence) in the context of quality improvement, including how they personally might have changed and what happened as a result. One study aimed to look at the experience of staff of taking part in a service improvement project in outpatient services for older people, but it explored their views on the EBCD method, rather than their reflections on how it affected them (Bowen et al., 2013). An evaluation of the use of patient narrative films in projects with intensive care patients and lung cancer patients in an acute hospital explored the impact on staff of watching the films. This was described by some staff as emotionally powerful and 'galvanising', and the authors concluded that just seeing patient narratives on film can in itself have a powerful effect, and can help staff to reconsider their behaviour towards patients. One of the films was described as making clinical staff 'sit up and take notice….showing the true, full experience and the enormity of what it's like to have lung cancer…what a person goes through.' (Adams, 2015 p.4). The authors commented that, as part of this experience based co-design project, the films also increased the motivation for both staff and patients to engage with the project in spite of being pressed for time in their clinical roles. However, their motivation levels were not formally assessed.

The rationale for experiential approaches to quality improvement, including shadowing, is that these methods can have a powerful impact on staff, and can change them personally, perhaps increasing their empathy for patients, and making them more motivated to want to make their patients' experience of care better (Point of Care Foundation, 2020). Studies which describe shadowing as a research or improvement approach do not generally describe this type of change in the shadower, except in relation to improved understanding of processes of care. Researchers may occasionally reflect on their improved understanding of the experience of being a patient, and how it feels somewhat awkward to be the one shadowing (van der Meide, 2013; van der Meide, 2015). In terms of quality improvement, only one paper was found which explicitly mentioned the emotional impact on staff in a QI project, citing increased empathy and motivation to improve patients' experience of care (Shaw et al., 2014) This project used the Patient and Family Centred Care method in a children's acute trust , and staff were asked to keep reflective logs during the course of the project. The authors commented:

> 'Shadowing appears to inspire staff to find innovative solutions and to feel positive about changes, and helps them challenge their expectations about what is important to patients and their families….helps develop relationships between patients, families and staff by allowing them to engage emotionally with patients' and families' experiences.' (p.21).

In the same children's hospital where medical students shadowed patients, it was found that patient shadowing could be a powerful medical education tool 'in helping medical students understand the demonstration and development of empathy' (Calvert et al., 2018). As Liberati (2016) suggests, it may be difficult to express difficult emotions about the impact of shadowing on oneself. She calls for 'more nuanced and more reflexive

….accounts of the experience of shadowing from multiple perspectives – observers, patients and caregivers’.

The theoretical literature which might shed light on why it is difficult for healthcare staff to express difficult emotions about their shadowing, or indeed why the process of shadowing might be difficult ranges across different disciplines, including psychology, sociology, anthropology, medical and nursing education. The psychology and some sociological literature suggests that defences are put up by healthcare organisations, but also by individual healthcare staff, to protect themselves against the anxiety caused by working in an environment where they are constantly encountering suffering, disease, disfigurement and death (Menzies-Lyth,1988; Campling, 2015). The act of shadowing may threaten these defences by putting a member of staff into a close relationship with a patient, which is different from the usual professional relationship. Indeed medical and nursing professionalism literature discusses the concept of professional detachment and whether professionalism requires a degree of detachment, or emotional distance from patients (Christianson et al., 2007). Even though professional detachment may not now be taught formally to medical and nursing undergraduates, detachment is recognised as part of the ‘hidden curriculum’ (Rajput et al., 2017) and as a mechanism for coping with the nature of the work healthcare staff do; too much unmanaged emotional involvement with patients can lead to burnout (Firth-Cozens and Cornwell, 2009; Gillespie and Melby, 2003; Wilkinson et al., 2017). In studies of trainee doctors for example, it has been noted that detachment increases over time, demonstrating a strategy that is operationalised for self-protection. The management of emotion in healthcare is also central to the concept of emotional labour, which acknowledges the work involved in putting one’s own emotions second in order to present a caring persona to patients (Msiska et al., 2014; Hochschild, 1983). The idea of maintaining emotional boundaries between professional and patient or client is central to training and practice in the psychological professions (Jones, 2000).

There is an implication that the right amount of empathy is important; too much might lead to burnout, but not enough means that the patients and indeed the professional could suffer (Wilkinson et al., 2017). On balance, empathy is encouraged and there is much discussion in literature about its place in the education and training of medical and nursing practitioners, particularly around the debate of whether empathy can in fact be learned and taught, (Ancel, 2006; Arthur et al., 2015; Kelm et al.,2014; Williams et al., 2015) and how this differs in relation to cognitive empathy (the way we understand) and affective empathy (the way we relate emotionally) (Halton and Cartwright, 2018; Baron-Cohen, 2012).

Anthropological literature includes accounts of ethnography and reflexive learning to gain insight into the experience of patients (van der Meide et al., 2013). The question of how healthcare staff are personally motivated to make changes for their patients is discussed in the health management literature as well as the quality improvement literature, and interventions which appeal to the intrinsic motivation of staff who want to provide better care for patients is advocated (Herzer and Pronovost, 2014; Janssen et al., 1999).

PART TWO

2.4. The context for the programme and its participants: operationalising patient experience

The participants were members of healthcare teams working in the NHS who were taking part in a programme to improve the experience of patients (and their families) at the end of life. They were not palliative care specialists and the majority were working in acute hospitals, with some in community and mental health trusts, and it is important to understand the policy drivers they would have in their organisations related to patient experience. This second part of the chapter draws on a review of the policy literature, included in the initial scoping review, and supplemented throughout the course of the study. It provides the context within which the participants in the study would be working in their different organisations.

2.4.1. What do we mean by patient experience? - definitions

Given the study participants' focus on improving patient experience, it is helpful first to deconstruct the term 'patient experience' in the context of guidelines and policy in England. The way a patient is treated as a person, and how they experience care has been a focus for campaigning patient groups over the last 20 to 30 years, particularly on behalf of vulnerable groups. For example, campaigners on behalf of frail elderly patients have been influential in raising the profile of patient experience. Help the Aged, a national charity, ran the 'Dignity on the Ward' campaign (Levenson, 2007) and the Royal College of Nursing carried out important work focusing on the dignity and privacy of patients (Royal College of Nursing, 2008). Dignity and respect were terms used by the 2012 Commission on Improving Dignity in Care (NHS Confederation, 2012). The language to describe aspects of patient experience has not been consistent, and has developed and changed, perhaps reflecting shifts in priorities. The NHS Constitution referred to compassion: 'the NHS touches our lives at times of most basic human need, when care and compassion are what matters most' (Department of Health, 2008. p.2), and soon after this policy makers began to talk about compassion and patient experience interchangeably. Words and phrases used by campaigners and activities included humanity, as well as dignity, respect and privacy, and compassion, and policy makers and academics have used patient-centred care, person-centred care, personalised care, relationship-centred care (Goodrich and Cornwell, 2008). These terms have different and nuanced meanings for different groups (in health, or social care, or social welfare policy for example), but this is not made explicit. For example, there is a body of literature related to relationship-centred care, a term used by academics to refer to the three-way relationship between patient, family staff in residential, nursing and care home settings (Nolan and Mock, 2004; Nolan et al., 2004). 'Person-centred care' is used in practice development in the nursing literature specifically to encompass both patient and nurse (Manley and McCormack, 2008). In social care, person-centred care or personalised care refers to the idea of a personalised budget held by the service user for their own care.

In terms of health services improvement, because the language is shifting and sometimes vague, attempts have been made to pin down what is meant by patient experience or patient centred care in order to be clear about what exactly should be measured and improved. Several official definitions and frameworks exist, but The Institute of Medicine's definition of quality in healthcare is recognised internationally and has six criteria: patient-centred, safe, effective, timely, efficient and equitable (Institute of Medicine, 2001). In turn, patient-centred care is broken down into six dimensions which were derived from research by the Picker Institute to find out what is important to patients (Gerteis, 1999; Delbanco, 1996). This was crystallised into six elements:

- Compassion, empathy and responsiveness to needs, values and expressed preferences
- Coordination and integration
- Information, communication and education
- Physical comfort
- Emotional support, relieving fear and anxiety
- Involvement of family and friends

As seen in the scoping review of the literature, research is uneven across these six elements of patient centred care, with most investment in research into communication between practitioner and patient (Stewart, 1995; Dwamena et al., 2012; Howick et al 2018; McDonald and Sherlock, 2016; Virdun et al., 2015; Brighton et al., 2019), although studies of end of life care also have an emphasis on emotional support and relieving fear and anxiety (Ó Coimín et al., 2019).

'Patient-centred care' was the language used for many years, but has been superseded in policy terms by 'patient experience'. The most current framework in England is the NHS patient experience framework (NHS National Quality Board, 2011) (see table 1), reflecting the move from the terminology 'patient-centred care' to 'patient experience'. This has built on the Institute of Medicine's definition, updated to reflect Picker's most recently added elements, access issues (such as waiting times) and transition and continuity issues (between NHS services). The framework covers both process, or transactional aspects of care (such as cleanliness or waiting times) and relational aspects of care (such as alleviation of fear and anxiety) (as defined by Murrells, 2013, p.2). It is interesting to note that phrases such as 'compassionate care' are used by policy makers and others as shorthand for good patient experience, without reference to, or knowledge of, the comprehensive set of dimensions of patient-centred care, or patient experience included in these frameworks. However, the use of the word 'compassion' shows recognition of the importance of relational care to patients.

Table 1: The NHS Patient Experience Framework.

- **Respect for patient-centred values**, **preferences, and expressed needs,** including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making.
- **Coordination and integration of care** across the health and social care system.
- **Information, communication, and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion.
- **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings.
- **Emotional support and alleviation of fear and anxiety** about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances.
- **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers.
- **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions.
- **Access to care** with attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

NHS National Quality Board (2011)

2.4.2. Collecting patient experience data

Although there has been long debate in the academic literature about the advantages and disadvantages of quantitative or qualitative methods to collect information on patient experience (Goodrich and Fitzsimons, 2019; Robert, Cornwell and Black, 2018; Robert and Cornwell, 2013), policy makers have favoured annual survey data, chiefly for monitoring and comparison purposes. The NHS national survey programme has been in place in England for the last seventeen years. It is run by the Care Quality Commission (CQC) and gathers data on a variety of care settings (such as maternity care, community mental healthcare, cancer services and inpatient care – but not palliative or end of life care). The biggest, the NHS Inpatient Survey, is a postal survey, carried out annually since 2002 by acute and specialist inpatient trusts. Each participating trust is responsible for selecting their own patients to survey and collecting data, in strict compliance with instructions issued by a central co-ordination centre. The survey asks about inpatients' care and treatment, with questions derived from the pioneering research carried out by Gerteis and Delbanco taken up by The Picker Institute, about what is known to be important to patients (Gerteis, 1993; Delbanco, 1996). The survey achieves approximately 70,000 responses each year (Care Quality Commission 2018). There is therefore a large amount of literature describing the 'problem', as these data are presented in annual reports for each NHS trust. There is some debate, however, about the purpose of these surveys, beyond use by NHS trust boards. Their primary intended purpose is for monitoring and benchmarking; thus NHS trust boards can monitor how they are doing over time, and compare themselves with other similar organisations.

The current policy priority on measurement for all trusts in England is NHS England's 'Friends and Family Test' (FFT). The FFT was introduced to all acute hospitals in England in April 2013, and soon extended to maternity, outpatient, ambulance, mental health, community, primary care, and dental services. The FFT asks the question 'how likely are you to recommend our services to friends and family if they needed similar care or treatment?' and respondents rank their reply from 'extremely unlikely' to 'extremely likely'. The FFT is not designed to be used for comparison and benchmarking between trusts, but can be used for monitoring patients' feedback about their experience of a particular service within a trust, and can be used in specific areas such as wards or

Accident and Emergency – in other words it is not a random sample of patients. Trusts are required to administer the FFT but can choose how and where to do this. There is a free text section, and these comments have sometimes been used for improvement (Robert, Cornwell and Black, 2018). However, the collection of qualitative data is not given the same weight in policy terms, and therefore there is less guidance about qualitative methods of data collection (which could include shadowing and observation), or incentives to use qualitative data.

The National Palliative and End of Life Care Partnership states that 'all those who are part of the local health and social care system that cares for the dying and bereaved should seek to sensitively collect and use a wide range of information so that they can assess progress towards our ambitions. Palliative and end of life care organisations need to……invest in collecting and using data' (National Palliative and End of Life Care Partnership, 2015, p.15). The VOICES survey, a national survey of bereaved carers, ceased in 2015 (Office of National Statistics, 2016). Locally, some hospitals and hospices send bereavement surveys to carers and family a few weeks or months after the person has died. The information collected through the shadowing approach used in the PFCC Living Well programme (focus of this study) contributes to this ambition.

2.4.3. The drive for improvement

Regular analysis of surveys of NHS patients in every NHS trust demonstrates that patients' experience is not consistently good and has scarcely improved in some area for some years (Care Quality Commission, 2018; Care Quality Commission, 2019). An analysis of surveys of NHS patients in every NHS trust (required by the Care Quality Commission), between 2005 and 2013 shows that some transactional elements of care have improved, and these tend to be where there have been consistent efforts related to a policy initiative, such as infection control, where the responses to questions on cleanliness have become more positive (Raleigh, 2015). Other aspects of care, particularly relational aspects, such as communication with patients, have remained around the same level over this time. This raises the question as to whether these annual surveys can be effectively used for quality improvement. Clearly, constantly measuring patient experience does not automatically lead to improvement. The reasons for this include that the data are analysed and often returned to organisations months after they were collected. The data are not local enough to know whether the patients' responses refer to a particular clinical area or ward, let alone time or shift. The sample surveyed may not represent the patients whose experience needs to be improved.

It could be argued that the government's drive for improvement has been influenced most by a series of public inquiries into poor care, which have revealed in some cases reports of shocking experiences for patients and their families. Public Inquiries and complaints processes collect stories from patients and families, which can have a powerful impact for change. Examples include the Bristol Royal Infirmary Inquiry (Kennedy, 2001) which looked into the excessive number of deaths of children undergoing heart surgery; the Morecambe Bay Investigation into the deaths of 11 babies and one mother in hospital maternity services (Kirkup, 2015); and the Winterbourne View hospital inquiry into the abuse of patients with Learning Disabilities (Bubb, 2014). The most influential was the Francis Inquiry, described as 'very narrow in scope', but with 'seismic ramifications' (Anandaciva, 2018). Robert Francis QC chaired a public inquiry, commissioned by the government in 2010 into the well-publicised poor care, particularly of vulnerable older patients, at Mid-Staffordshire NHS Trust. Hundreds of accounts of experiences were collected from patients and their families which showed that at different times, all the dimensions which make up the definition of patient experience were poor. Many of the patients were frail and elderly, and the quality of their experience of dying in hospital was traumatic for them and their families.

2.4.4. What the government expects healthcare staff to do – the policy context

Government policy on patient experience has a number of strands. There has been an element in the policy environment (separate but often conflated with 'patient experience' initiatives locally), which has been in response to patient groups campaigning for patients' voices to be heard in relation to their care, and in the governance of healthcare. Government policy has used language like the phrase 'no decision about me, without me', the title of the consultation exercise following the White Paper, Equity and Excellence: Liberating the NHS (which preceded The Health and Social Care Act 2012). The White Paper stated that it set out 'the Government's vision of an NHS that puts patients and the public first' (Department of Health, 2010). The NHS Long Term Plan published in 2019 referred to how the NHS 'needs a more fundamental shift in how we work alongside patients and individuals to deliver more person-centred care, recognising – as National Voices has championed – the importance of 'what matters to someone' is not just 'what's the matter with someone' (NHS England, 2019). This concept tends to be related to individual patient care and shared decision making rather than improving a service for all patients. Patient and public involvement (PPI) is another broad concept and can range from token involvement in a service, to working with patients as real partners (Ocloo and Matthews, 2016). However, these different policies and concepts are not always clear, and moreover, within healthcare organisations, PPI is not usually situated together with quality improvement initiatives, and so situations arise where efforts are made to improve patient experience without the involvement and engagement of patients, or attempts to understand 'what matters to someone'. (Ocloo and Matthews, 2016; Robert and Cornwell, 2013).

The recent policy prioritisation of end of life care helps to explain why the programme in which study participants were enrolled was commissioned by NHS England. Government policy related to end of life care includes the first national End of Life strategy that was published in 2008, and in 2015 a new framework that was published building on this, setting out six ambitions, all accompanied by a statement framed from the perspective of the person who is at the end of life (National Palliative and End of Life Care Partnership, 2015). The first ambition is:

> 'Each person is seen as an individual. "I am asked what matters most to me. Those who care for me know that and work with me to do what's possible"'.[5]

The framework emphasises the importance of those close to the patient at end of life and states that 'the need for support from empathetic and competent health and care staff is as important for carers, families and those who are bereaved, as it is for the dying.' (p.18).

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[5] The others are: Each person gets fair access to care; Maximising comfort and wellbeing; Care is coordinated; All staff are prepared to care; Each community is prepared to help

The policy context for the teams in the study is, broadly, the focus on patient experience as a crucial component of quality in healthcare. Quality improvement has been a policy priority ever since the government commissioned Lord Ara Darzi's review, 'High Quality Care for All' (Darzi, 2008). Darzi set out the three pillars of quality of care: patient safety, patient experience, and effectiveness of care. This follows on from the work of the Institute of Medicine which referred to patient-centred care, and from earlier work where the criteria for good quality for health services were 'humanity, efficiency, effectiveness and equity' (Open University U205 Team, 1985; Maxwell, 1992). Current directives from the Department of Health and more recently NHS England and NHS Improvement have urged NHS leaders to address the problem of poor patient experience (NHS England, 2019). In spite of this, quality improvement programmes, projects, interventions, approaches and methods have been developed predominantly to improve the clinical quality and safety of healthcare, with less emphasis and investment in patient experience. Indeed, Darzi's review pointed out that progress had been made on safety and effectiveness but that 'progress has been patchy, particularly on patient experience'. The policy climate for staff in the NHS has been orientated towards measuring patient experience, rather than understanding and improving it (Duschinsky and Paddison, 2008).

2.5. Summary

This review of policy related to the quality of patient experience, and the drivers to improve it, has revealed the wider context for the teams in this study. More specifically, the national Ambitions for Palliative and End of Life Care call for a wide range of information to be collected by those caring for patients at end of life. The review has demonstrated that the programme the study participants took part in (Living Well) was unusual because of its premise that in order to improve what matters to patients and their families, and to identify what would make a difference to their immediate experience, it is necessary to discover the experience from their perspective, and as close to real time as possible.

The scoping review of the research, practice and theoretical literature had some limitations: for example it excluded papers that were not written in English, and the body of literature in specialist palliative care, focusing instead on end of life care in non-specialist contexts. The review of the theoretical literature necessarily had a narrow focus, although theory from many other disciplines could be relevant, and could contribute to discussion in future. Nevertheless, it can be concluded that the impact on staff who take part in projects (especially using experiential methods such as shadowing) to improve patient experience is an under-researched area. Indeed other researchers have called for a focus on 'deeper, longer changes in attitudes and behaviours' (Robert et al., 2015, p.2). This study examines for the first time, through the detailed accounts of healthcare staff, the experience of taking part in a programme which requires them to use the experiential technique of shadowing patients, including the challenges and rewards. The study explores how the experience of shadowing might bring about change for staff personally, and how its impact might affect the motivation to improve patient-centred care. The literature has also demonstrated that there are many accounts of projects by researchers and others, which do not provide the detail of how the improvement approach was put into action, and then how changes in patient experience came about. This study will examine both the process of shadowing and its effect on change for patients, and the next chapter describes the methods adopted to achieve this.

CHAPTER 3: METHODS

3.1. Introduction

This research uses semi-structured interviews to explore the experience and impact of shadowing patients, with a purposive sample of 20 healthcare staff who took part in a collaborative learning programme to improve the experience of care for patients at the end of life. The qualitative data were analysed using Thematic Analysis (TA) (Braun and Clarke 2006; Braun and Clarke, 2013). A short quantitative survey was administered to all the programme participants at the start and end of the programme. This chapter has seven sections: the first section provides an overview of the setting, aims and objectives of the study in order to put the rest of the chapter in context. The second section describes the study design and rationale for a mixed methods, predominantly qualitative approach; the third section discusses the researcher's assumptions in relation to the study; the fourth section describes ethical issues; the fifth section describes the sampling approach, recruitment and data collection; the sixth outlines the particular method of data analysis (TA) for the qualitative data, and the seventh, final section, summarises quality assurance.

3.2. Background to the study

The focus of interest for the study was members of nineteen multidisciplinary healthcare teams from across England who took part in a quality improvement programme led by The Point of Care Foundation (PoCF), a small not for profit organisation which works to improve the experience of patients and staff in the NHS. The Patient and Family Centred Care (PFCC) programme has been taught three times since 2010 and this fourth programme, focused specifically on quality improvement in end of life care. (See appendix B for further description of programme). The programme participants were not necessarily palliative care specialists, but cared for patients at the end of life in a variety of healthcare settings. The programme ran from July 2017 to April 2018. A key part of the PFCC's approach is the requirement for healthcare staff to shadow patients in their service to inform their understanding of how the experience of care can be improved (DiGioia et al., 2007). Shadowing is an interactive process, and involves accompanying a patient for a part of their day[6], to observe and share their experience of care.

The aim of the study was to explore the impact on healthcare staff of shadowing their patients (and families), as the key component of a quality improvement method 'Patient and Family Centred Care'. The objectives were first, to explore the relationship between shadowing, knowledge, understanding and empathy, and motivation to make improvements, and secondly, to understand the process of shadowing and how acceptable it is for staff (in other words whether they found any challenges in the method, and how willing they were to undertake it). The third objective was to produce practical guidance for future healthcare teams.

3.3. Study design and methods

This section describes the study design and explains the methods chosen, and the time frame for the study. The study is designed to explore the perceived impact of shadowing on the individual shadowers, which may or may not contribute to achieving the programme's goal of improving patients' and families' experience. The study is not an evaluation, although may have elements of a 'goal-free' evaluation (Patton, 2002, p.169) in that it explores *whether* it brings about change for them personally, and what the relationship might be between changes in the individual's understanding (or knowledge), empathy and motivation. This in turn might bring about improvements in patient care, but it is not an explicitly goals-based evaluation (Patton, 2002).

The research design was guided by a Continuum of Social Research framework which describes all elements to be taken into consideration including the underpinning philosophy, research question, sampling, data collection methods, data format, analysing and coding, goals of analysis and presentation of data (Draper, 2017, appendix C). This framework confirmed that a qualitative approach fitted best with the research questions and focus of the study. An experiential qualitative research approach

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[6] Participants could choose to shadow for however much time they could spare, and this varied within the sample from one session of half an hour to seven sessions of over one hour each

prioritises and validates participants' interpretations of their experiences. Braun and Clarke describe the fundamentals of qualitative research, one of which is that it deals with, and is interested in meaning, and accounts are collected from participants in a specific context, which itself is seen as important (Braun and Clarke, 2013, p.21). The study aims to evaluate attitudes, understanding, feelings and emotion, and motivation, and a qualitative approach is the most appropriate way to explore experiences and their perceived impact (Braun and Clarke 2013; Patton 2002; Robson, 2015). Given the sensitive nature of the topic, it was decided that data collection would be through semi-structured one to one interviews, where it was felt that participants would feel able to express their feelings more freely than in pairs or focus groups. Moreover, it was thought that if focus groups were organised by project team, the presence of team leaders or managers might be an inhibiting factor for more junior members of staff.

An ethnographic approach was considered in addition to interviews, which would have involved the researcher following and observing the participants as they shadowed patients and families. However, it was felt that introducing an additional person observing others who were in turn observing patients would have been impractical and inappropriately intrusive for patients, many of whom were in small side rooms.

Data collection also included a short quantitative questionnaire to provide context for the qualitative research; to gather baseline data on knowledge and attitudes to shadowing, and self-rated empathy before starting, and repeated after shadowing was complete in order to monitor any changes, and to assist with purposive sampling for the interviews (appendix D).

3.4. The researcher's assumptions

In order to be explicit about the place of theory and the researcher's assumptions in relation to the study, this section describes how the research design was influenced, what theories underpinned the methodology, and the implications of theory for how data were analysed and interpreted (Kelly, 2009).

The Point of Care Foundation's logic model provided assumptions which influenced the research design. This logic model was worked up and explicitly expressed as part of wider work on developing the Point of Care Foundation's Theory of Change (Point of Care Foundation, 2017). The logic model posits that if staff use the experiential approach of shadowing they will understand the experience of care from the patients' and families' point of view, and as a result will become engaged in making improvements to the service which will benefit patients. The researcher discussed the research questions for this study with work colleagues in light of this. It was felt it would be valuable to test this logic model, taking an exploratory qualitative approach to provide insight into the mechanisms in the model and test its assumptions.

This study takes a contextualist or critical realist approach, in that it acknowledges the ways that individuals make sense, or meaning of their experience of shadowing, and how they describe the phenomenon, how they feel about it, remember and judge it (Patton, 2002 p.104) and that the context in which they were shadowing has an influence. Most of the interviewees in this study were reporting an experience seen through their own different lenses (professional, and personal life experience). However, at the same time they describe or report the material, functional or 'authentic' realities of experience that would remain the same, whoever observed them, such as time taken for procedures, or the length of time patients have to wait for appointments or procedures.

Epistemology is concerned with what counts as 'legitimate' knowledge, i.e. what to believe or trust, and there are necessarily epistemological assumptions underpinning qualitative research. In this case the question was, '*to what extent could the researcher trust what she was told as a 'true account'?* It was important to be aware that the context may influence what the researcher was told; this was a professional doctorate and the researcher was close to the programme (as discussed elsewhere, section 7.2), so it was possible that the study participants were conscious of that, and constructed what they said, adopting a particular position, and may have been leaving information out. However, the assumption has been that steps were taken to reassure and put them at their ease, and while needing to be aware of the possibility, this has generally not been the case. In addition the researcher was aware that knowledge is contextual (as well as partial) emerging from different situations – but was 'true' in that context.

3.5. Ethics

Before starting any data collection a request for ethical approval was submitted to the University of Westminster's research ethics committee, and was granted on 29th June 2017 by the Faculty Research Ethics Committee (appendix E). NHS ethics approval was not needed for this study. The participants were recruited via the Point of Care Foundation's programme, rather than through NHS trusts directly, and in answer to a query submitted to the Health Research Authority queries line (18th April, 2017) it was confirmed that the research did not require a REC review.

A range of issues was addressed to make sure the study was conducted ethically. Participant Information sheets were provided with the survey at the events where participants were invited to complete the questionnaire, and time was given to them to read it first, and to ask any questions (appendix F). Participant Information sheets and informed consent forms were sent out with email requests to potential participants for the qualitative interviews (appendix F). Before these interviews commenced it was checked with the interviewee that he or she had read and understood the information and the consent form before signing. The information explained that taking part in the study was completely voluntary and that they did not have to answer questions they did not want to and could withdraw at any time from the study. They were assured verbally that the recording of the interview was purely for the purposes of transcription and, although included on the consent form, they were asked again whether they were happy to be recorded, and asked whether they wanted to see and comment on their transcript. None wished to see their transcript.

The research focuses on the experience of shadowing patients, and in most cases the patients were dying, which raised issues that were potentially upsetting for the interviewee. The researcher was careful to note whether any participant became distressed, and would have offered to stop the interview if this was the case, or take a break. More time for this was allowed when planning interviews. However, this did not happen. All participants were provided with the researcher's contact details in case they had any questions and the information sheet explained that complaints about the study could be directed to the researcher's supervisor and contact details were provided. Participants were asked again at the end of the interview whether they wanted to see a copy of the transcript, and all will be given the opportunity to request a summary of the study report upon completion. Confidentiality was ensured and participants' anonymity maintained, through assigned numbers rather than names. Only the researcher had information to link their name with the anonymous number their interview or questionnaire was allocated. The preamble to the survey clearly explained that their data would be anonymised. Interviews were recorded and transcribed either by the researcher or a third party (commercial transcription service). Where the interviews were transcribed by a third party there was a confidentiality agreement. One copy of the recordings of the interview were stored in a locked safe and all other recordings deleted once transcribed. The anonymised scripts were stored in files on the researcher's password protected personal laptop and personal desktop. When the project is complete, electronic files will be copied to memory sticks (and then deleted from desktop computer and laptop) and stored under lock and key with any paper files, for three years, and then destroyed.

3.6. Sampling, recruitment and data collection

When choosing the sample it is necessary to consider 'a) *how much* data we need;
b) how we select our sample and c) how we recruit participants' (Braun and Clarke, 2013, p.55). These questions are addressed in this section for the quantitative data first, followed by the qualitative data.

3.6.1 Quantitative sample and data collection

The time frame for the study was determined by the timetable of the Quality Improvement programme whose participants were the focus of the research. The programme included three events: learning events in July and October 2017, and a final celebration event in February 2018. Nineteen multidisciplinary teams took part in the programme and were invited to choose and bring three people to each event. Short questionnaires were administered to all participants at the first and last events. The

PFCC Living Well event organisers provided a short amount of dedicated time in the day's programme for the survey to be completed by participants, after which the researcher collected the completed paper questionnaires. This was for pragmatic reasons; from previous experience of running these programmes and sending out simple feedback forms for completion, the PFCC Living Well programme leader recommended this as a way of getting the best response rate. She was reluctant for the participants to be overloaded with 'paperwork' in addition to what they were being requested to complete and return electronically as part of the programme.

A response rate of 82% was achieved at baseline and 72% at time 2.

Table 2: Survey response rates

	No. of participants	No. of responses	Response rate
Time 1	51	42	82%
Time 2	46	33	72%

The survey was administered to all those who attended the first learning event of the programme in July 2017, with the assumption (later to be proved wrong) that they would nearly all attend the other learning events, so that the repeat survey would be administered to the same participants at the third and final event in February 2018. Participants had been asked to provide their names (then allocated a number by the researcher) so that they could be identified for the follow-up. Although teams from the same 19 organisations attended, only fifteen participants completed both the baseline and second survey. Of these, seven had done shadowing and eight had not. One reason for the low number of possible repeats was that some (n=15) did not provide a name but the main reason was unexpected: that different people attended the final (T2) event, either because of staff turnover during the project, or because it was not possible for all members to attend because of work pressure. Other teams had deliberately decided to allow different members to attend because a day away from their workplace was seen as a reward that should be shared fairly.

3.6.2. Developing the questionnaire

The aim of the questionnaire was to provide context for the qualitative study, and to help to identify participants for the qualitative study. The first section of the questionnaire included demographic questions including gender, professional background and length of service in healthcare. The remaining six questions were designed to assess four areas:

- the level of confidence or anxiety related to shadowing patients among programme participants (Likert scale, 1-5)
- the understanding staff have (or think they have) of the experience patients and families have in their particular service (Likert scale 1-5)
- the feelings staff have about shadowing (a choice of words to circle, plus free text)
- self-perceived empathy

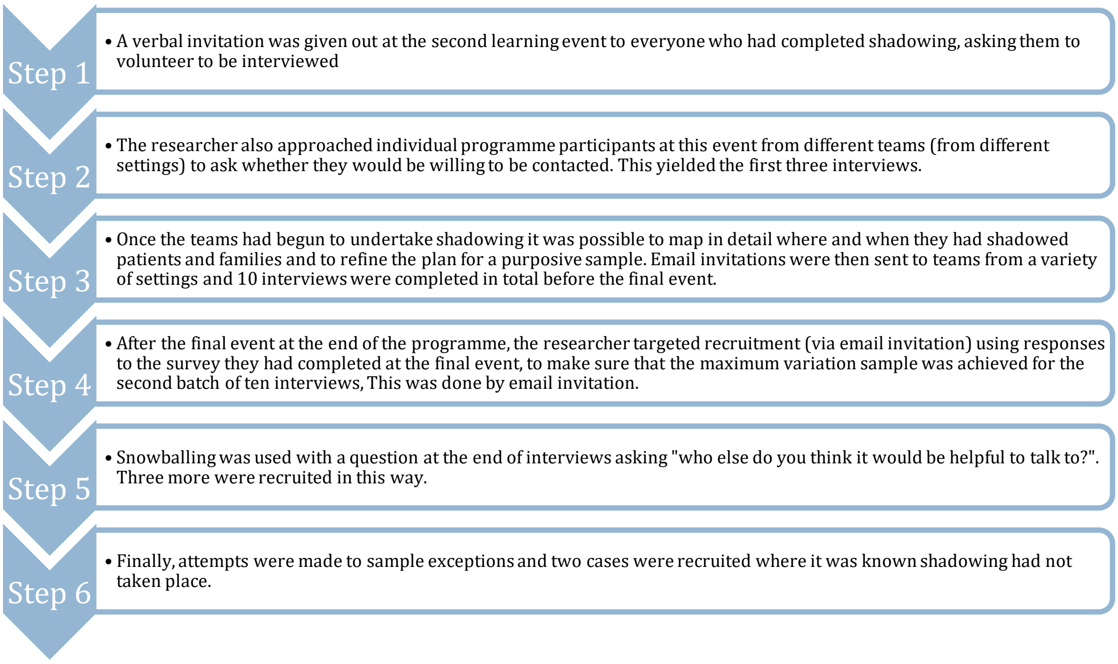
Empathy was assessed using 5 items from an empathy scale: items 13-17 taken from the Empathy Quotient measure developed by Baron-Cohen and Wheelwright (2004). This measure was developed for adults with high functioning autism but has been adapted to become a subscale (with these five items) which has been used in research with healthcare staff. The word ‘people’ has been changed to ‘patients’ so that participants situate their responses in a work context. Advice was sought from researchers who have used the subscale with staff in the NHS, who advised that it has good alpha reliability (.805) and good face validity and was a good fit with their understanding of empathy as it relates to the practice of healthcare professionals (see Maben 2018, for an example of its use). There are four response options ranging from 1 ‘Strongly disagree’ to 4 ‘Strongly agree’. An example item is ‘I am good at predicting how a patient will feel’.

The questionnaire for the short survey was piloted with two colleagues (who did not complete the revised survey), question by question, and slightly re-worded as a result. The data were transferred from paper copies of the quantitative survey and entered into SPSS by the researcher for analysis.

3.6.3. Qualitative sample and recruitment

For the qualitative study, purposive sampling was employed, namely maximum variability sampling, whereby a wide range of cases was purposefully selected in order to get variation on key dimensions of interest (Patton, 2001, p.243). Specifically, an effort was made to recruit individuals from teams working in the widest possible variety of healthcare settings, from varied professional backgrounds and length of experience. Although all teams in the Living Well programme were working with patients at end of life, there was a range of settings, including hospital, community and mental health, and hospice settings. The teams were made up of staff with different clinical and non-clinical backgrounds, with most not having palliative training. Most, but not all, had jobs which involve direct patient contact. The programme participants ranged from senior staff who had worked in the NHS for decades, to junior staff who had been working for less than ten years. The sampling frame was all programme participants, and was estimated to be 95 people (19 teams of five, including those who did not attend the programme events).

The sample was built up through recruiting participants in a series of steps:



Step 1
- A verbal invitation was given out at the second learning event to everyone who had completed shadowing, asking them to volunteer to be interviewed

Step 2
- The researcher also approached individual programme participants at this event from different teams (from different settings) to ask whether they would be willing to be contacted. This yielded the first three interviews.

Step 3
- Once the teams had begun to undertake shadowing it was possible to map in detail where and when they had shadowed patients and families and to refine the plan for a purposive sample. Email invitations were then sent to teams from a variety of settings and 10 interviews were completed in total before the final event.

Step 4
- After the final event at the end of the programme, the researcher targeted recruitment (via email invitation) using responses to the survey they had completed at the final event, to make sure that the maximum variation sample was achieved for the second batch of ten interviews, This was done by email invitation.

Step 5
- Snowballing was used with a question at the end of interviews asking "who else do you think it would be helpful to talk to?". Three more were recruited in this way.

Step 6
- Finally, attempts were made to sample exceptions and two cases were recruited where it was known shadowing had not taken place.

Fig.3. Recruitment process

At the last event marking the end of the programme, participants completed a second survey, and the responses helped to identify a range of positive and negative attitudes to, and experiences of, shadowing. The researcher then targeted recruitment (via email invitation) to make sure that the sample included this variation (step 4). Three did not reply, in spite of being contacted with follow-up emails three times, two agreed to be interviewed but did not respond to further emails to arrange a time, and one cancelled due to a bereavement. It was suggested by two interviewees that the programme coaches would yield valuable information; these are individuals who have undertaken the programme (including shadowing) successfully before, usually team leaders locally, and were recruited by the PoCF to provide peer coaching. They were experienced shadowers and three were recruited and interviewed towards the end of the fieldwork (step 5), partly in order to explore ideas in more depth which were emerging from the coding exercise (see data analysis). This illustrates what Patton (2002) describes as how the 'exploratory process gives way to confirmatory fieldwork' (p.239)

There was one example of opportunistic sampling when a colleague at a QI seminar suggested interviewing a colleague at her hospital who ran a leadership programme which incorporated shadowing as a mandatory element; it was thought this could yield interesting information about shadowing non end of life patients. This was helpful to test variation.

Table 3: Sample characteristics

Background	Organisation	Shadowed Y/N	Type of interview
Non-clinician, programme manager	Charity	Y	face to face
Volunteer/carer	Acute hospital	Y	telephone
Nurse/QI lead	Acute hospital	Y	telephone
Doctor (consultant)	Acute hospital	Y	telephone
Non-clinician, service improvement manager	Acute hospital	Y	face to face
Doctor (consultant)	Acute hospital	Y	face to face
Non-clinician, clinical improvement	Acute hospital	Y	telephone
Commissioner (non-clinical)	CCG	Y	telephone
Commissioner (nurse)	CCG	Y	telephone

Healthcare assistant	Nursing and care home	Y	face to face
Occupational therapy/HCA	Acute hospital	Y	face to face
Physiotherapy manager	Community hospital	N	telephone
Nurse trainer	Acute hospital	Y	face to face
Nurse	Hospice	N	face to face
Nurse	Community and mental health	N	telephone
Head of Patient Experience (clinical background)	Acute hospital	Y	telephone
Nurse (learning disabilities)	Primary care	Y	telephone
Patient experience manager (non-clinical background)	Charity/NHS	Y	Skype
Nurse	Acute hospital	Y	telephone
Patient experience manager (non-clinical background)	Acute hospital	Y	telephone

Variation in gender within the sample was reflective of the make-up of the healthcare workforce (NHS Employers 2019)[7]. 19 women were interviewed, and one man. The majority of the programme participants were female (with six men attending the first event, out of a total of 51 and six attending the final event, out of a total of 46). The survey responses offered limited opportunities for recruiting male interviewees; of those who completed the survey at the final event, only two were men, and only one of those had done shadowing (and had not completed the baseline survey). Two males were found through snowballing, and one of these consented to be interviewed.

In considering sample size, based on previous research we aimed to conduct around 20 interviews. In comparable studies discussed in the literature review saturation was reached at or below this number (Tsianakas et al., 2015; Locock et al., 2014). In the current study, interviews 16 and 18 produced new codes in analysis but the final two did not, suggesting data saturation.

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[7] https://www.nhsemployers.org/engagement-and-networks/health-and-care-women-leaders-network/women-in-the-nhs

3.6.4. Developing the interview guide

This section describes the development of the interview schedule for the semi-structured qualitative interviews (see appendix G, interview schedule), the primary research method for this study. The opening question was designed to put the interviewee at ease by asking about their role in the organisation, and how they came to be involved in the programme. Next they were asked about shadowing, starting with questions about the process, moving on to more sensitive questions about how they felt beforehand, and during the process. More specific questions about what they observed during the process were followed by questions inviting the interviewee to reflect on the process. A change of topic was signalled before two or three questions about experiential learning and empathy. The tone of the questions changed again at the end to become more practical, asking for advice or tips for others in the future, and the closing question explained the interview was coming to an end and asked whether there was anything they would like to add.

A funnelling pattern is recommended for qualitative interviews, with questions moving from the more general to the specific and this guided the sequence of questions, although having piloted the interview schedule, some questions were rearranged so that they were grouped into a series of funnels, or inverted triangle patterns questions (Braun and Clarke, 2013, ch.4), moving from general to specific. After two or three interviews it was found that it was helpful to follow the questions about emotions or feelings with questions about practical issues, and then return to more sensitive questions.

The qualitative interview schedule was piloted with two participants from the previous PFCC programme, and some questions re-worded. In particular the questions about empathy were changed more than once because they did not appear to be understood well. For example the question, ‘How do you relate to patients’ or families experiences?’ was changed to two questions ‘How do you think you understand and empathise with patients’ experiences?’ and ‘How much do you think you understand and empathise with their family’s experiences?’ The word ‘relate’ did not work well, and it became clear that interviewees might have different things to say about understanding patients’ experiences and understanding their family’s experiences (this worked better for those who were not clinical interviewees but might have had experience of visiting their family members in hospital). The question, ‘Thinking about the concept of empathy, what does this mean to you?’ was too broad, and was changed to a more specific question, ‘What does empathetic care mean to you?’ which was still somewhat abstract and was changed again to ‘could you describe an example of empathetic care that you have observed?’ (either when shadowing or another time). This led on better to questions about whether they thought shadowing helped them to empathise better, or could help others, and whether they thought empathy could be taught, and whether they had ever had any professional training intended to increase empathy.

The first question had been ‘Can you tell me about your experiences of shadowing’. This was too abrupt and the interview schedule was changed so that the first question ‘Can you tell me a bit about yourself, and your role here’ (which often elicited a long answer and which helped to establish rapport). The next question was then amended to be ‘Can you tell me how you came to do shadowing?’ followed by questions about the shadowing process in more detail. The wording of questions continued to be reviewed after each interview and notes were taken and words changed or refined accordingly. Prompts and probes were included after most questions, and these were also improved and a range of new ones added, and used when judged appropriate.

3.6.5. Qualitative data collection: interviews

Half the qualitative interviews were carried out within the time frame of the formal programme (between the second and third learning events in October 2017 and February 2018), and then the other half after February 2018 i.e. when the formal part of the programme was ended. This two phase approach was intended to capture initial reactions to shadowing, particularly logistical issues, and then later reflections on how shadowing may have impacted on both personal practice and improvements to the service. The same interview schedule was used at these different times, with some iterative adaptations. For example it became apparent that there had been a number of anxieties before shadowing began, so questions were added about whether these had turned out to be justified in practice.

Interviews were carried out at the participant's place of work, or by Skype or telephone, depending on what was most convenient or preferable for them and practical for the researcher. For example, one participant in rural Wales suggested Skype as an alternative to a telephone interview as she was used to using it for many of her professional meetings. The advantages and disadvantages of VoIP (Voice over Internet Protocol) technologies have been documented (Lo Iacono, 2016) and it would have been preferable in many cases to use this instead of telephone, but where participants were speaking from NHS premises, Skype or FaceTime proved to be problematic due to the poor signal in hospital buildings, as well as restrictions on NHS staff being allowed to have a Skype account. Out of 20 interviews, 7 were face to face (at their workplace in a private space), 12 were by telephone (3 participants at home, 9 at work) and one was by Skype (at home). Efforts were made to do face to face interviews as it became clear that these were more 'successful'; it was easier for the researcher to establish a rapport with the interviewee and to pick up on non-verbal cues to know when to probe or pursue a point further, which led to more personal insights.

The telephone interviews where the participant was at home worked better than when they were at work. Although all (with one exception where the participant was unable to find a quiet room and was therefore speaking from an open plan office) did take time out and found a private room at work for the telephone interview, there was a sense that it was more difficult for them to focus on the more reflective questions. The researcher always interviewed the participants at a time which suited them, but it was noticeable that if they were at home, or the interviews were face to face they felt under less time pressure and were happy to talk for longer and in more depth, (an average of 49 minutes for telephone interviews at home compared with 35 minutes for telephone interviews at work). Face to face interviews conducted in the workplace averaged 41 minutes. The longest interview was a Skype call (84 minutes) to the interviewee's home.

3.7. Data analysis

Thematic Analysis (TA) was chosen as the method for analysing the qualitative data. Other approaches were considered, including IPA (interpretive phenomenological analysis) and Grounded Theory. IPA is an idiographic approach and is appropriate when studying individuals in depth, and analysing data from a small number of individuals in great detail. A grounded theory approach intends to generate plausible new theory in relation to the phenomena found in the data. TA allows the researcher to find shared themes across a diverse sample, and was chosen because it was important to analyse a broad range of experiences from a sample of individuals with diverse professional backgrounds, working in different end of life settings. This would contribute to drawing out implications for practice, and robust recommendations to be made for future teams, one of the objectives of the research (rather than producing new theory). Moreover, the focus of the study is an under researched area and so it was important to analyse themes across the whole data set.

TA is described by Braun and Clarke (2006) as having theoretical freedom (independent of theory and epistemology), not wed to any pre-existing theoretical framework which makes it flexible and a method which can be applied across a range of approaches/within different theoretical frameworks (p.9). Its flexibility meant that TA was suitable for the exploratory nature of the study (which was not intended to generate new theories, therefore grounded theory was not an appropriate approach). Braun and Clarke state that TA can be an essentialist (or realist) method, or a constructionist method, or it can be a 'contextualist' method which sits between the two, which was the approach taken in this study. Thus TA can be a method which works both to 'reflect reality and to unpick or unravel the surface of reality' which was appropriate for this study. Braun and Clarke emphasise that it is important that when using TA, researchers make their epistemological and other assumptions explicit. (2006, p.5). Qualitative research is underpinned by ontological assumptions about how reality is perceived, given the relationship between the world and our human interpretation of it (Braun and Clarke 2013 p.27).

The data from the qualitative interviews was transcribed and then analysed using a thematic analysis (TA) approach, following Braun and Clarke's six steps:

1. The interviews were transcribed and checked; each one was read at least twice to check the transcript against the recording, and was part of the process of becoming familiar with the data before coding began.

2. A complete coding approach was taken; the transcripts were read through again and coded by hand line by line. Data-derived codes were created, followed by researcher-derived codes (latent codes), which were created through identifying implicit meanings in the data, drawing on the researcher's professional experience and literature.

3. Codes were grouped into initial themes, and these were in turn grouped into a smaller number, by setting them out visually and noting where there were overlapping themes or subthemes. The structure and hierarchy of themes was also shared and discussed with work colleagues. In TA data are coded, described and mapped as far as possible without bringing the researcher's assumptions to the exercise. Once the data are developed into themes, however, assumptions which draw on knowledge and theory (in this case both professional and derived from the research literature) inform how the themes might relate to each other and how the data might be interpreted. Thus themes are identified in both a bottom up way (data-driven) and top down, where the researcher uses the data to explore particular theoretical ideas, or brings these to bear on the analysis (Braun and Clarke 2013, p.178). Discussion with supervisors aided this iterative process. Conversations with colleagues with previous experience of programmes similar to the one in the study were also helpful for this process.

4. Transcripts were read again to check themes against the coded extracts to make sure that the whole data set was covered, and that there were no possible new themes.

5. Themes were checked again with supervisors and work colleagues. They were then used as headings for the outline of results chapters. This process revealed how the themes related to each other and how they helped to tell an overall 'story'.

6. The final write-up of results involved selecting example extracts from the coded transcripts for each of the headings, checking that they linked back to the research question.

3.8. Quality Assurance and my position as researcher

Quality was assured in a number of ways, following a set of quality principles outlined by Yardley (in Braun and Clarke 2013, pp290-292), which include sensitivity to context, in this case end of life care; commitment and rigour through data collection and analysis, and engagement with the topic; and transparency and reflexivity. As a professional doctorate, being clear about impact for policy and practice was a priority. Quality was also assured through taught sessions as part of the professional doctorate programme, and supervisions; data analysis was undertaken as an iterative thematic approach with discussion with supervisors who coded the first two transcripts with me which we then discussed. Further codes that I developed were then checked against sample transcripts and themes refined into fewer broader themes and subthemes. The structure and hierarchy of themes was also shared and discussed with work colleagues responsible for the quality improvement programme which was the focus of the study. Inevitably I was the sole collector of data, and so it was important to pilot the interview questions and share early transcripts.

An effort was made to find participants who might provide negative cases; the purposive sampling approach ensured that people who had decided not to shadow were identified through the survey, and some were sampled who had shadowed but said it had not changed their attitude to shadowing. To try to avoid the potential pitfall of the purposive sample being in one context, participants were found who had shadowed in a variety of healthcare services before shadowing in end of life settings for this programme. This was important particularly because of my professional relationship with the organisation which provided the programme. This is discussed further in the next section.

Reflexivity is the recognition that the researcher is part of the process of producing the data and their meanings (Green and Thorogood, 2018). It is essential to be conscious of the political, social, ideological origins of one's own perspective as a researcher and how this will influence data collection and bias in shaping findings. This section examines these issues, and discusses first the insider perspective of being professionally linked to the research, and what this means.

I am familiar with the PFCC programme, having been, as a member of the quality improvement team at the Point of Care Foundation, involved in the previous programme. My role then was to be allocated to two teams to monitor and support their progress. One was at an acute hospital and the other a community team. This gives me 'insider status', with its attendant advantages and disadvantages (Kerstetter, 2012; Dwyer and Buckle, 2009; Braun and Clarke, 2013; Robson, 2015; Patton, 2002). One obvious advantage was relatively easy access to the research participants. It meant the participants were willing to be interviewed, knowing that I worked at the organisation that was running the improvement programme and which they trusted. I was able to distribute the survey at learning events, and introduce myself at the same time, before approaching participants to request interviews. The main advantage, however, is the understanding of how the programme runs, what is expected of teams who take part, and the challenges they have, particularly in finding time to undertake the tasks set between the learning events. I believe this helped to establish a rapport with the interviewees, and helped in probing further with questions to deepen the conversation. I am aware of the practical challenges, and the anxieties teams have about shadowing patients and families, which assisted with designing the interview schedule. I have also, in past programmes, heard and seen at first hand the positive effect shadowing can have on individuals and teams, and so have a positive view of shadowing.

Being familiar with shadowing, and having personal views about it could also, I am aware, be a disadvantage. It could be difficult to be objective, when hearing about good examples in interviews, but more so when hearing negative experiences or opinions about shadowing. In addition I was conscious that I should not judge the way the shadowing was undertaken or what was said about it (for example if I knew the shadowing had not been carried out in the way the PoCF suggests and therefore might not have been very effective), and to resist the temptation to query this too strongly in the interview. This highlights the potential pitfall for a professional doctorate researcher– the necessity to remove the professional 'hat' and be detached from the work undertaken by the team members who are now the subject of a study. Previously, if I had heard that programme participants were struggling with an aspect of the improvement method, my role would have been to coach them. Overall, knowing the investment my colleagues at the PoCF put into the programme, means that, as a colleague I naturally wanted the teams to 'succeed'. To minimise my own personal investment in the outcomes, I stepped back and did not participate in the programme.

In terms of personal, rather than professional experience, I was aware that I might see things through the lens of my own role as a carer for my aunt, who had dementia and spent time in hospital (where she was not always treated respectfully) as well as being cared for at home, where she died. When I was involved in previous PFCC programmes I know that this experience (ongoing at the time) was an asset, because it informed my understanding of the frustrations and difficulties patients and families can have, particularly in trying to arrange care for someone at the end of life, and of my wish to make this better. I know that as a researcher I needed to be aware that this inevitably had a bearing on how I might interpret what I learned from the study participants, but that it afforded me useful insights and helped me to more sensitive, as an insider, to issues they spoke about.

CHAPTER 4: RESULTS (1)

The experience of shadowing: observations, attitudes and feelings about shadowing

4.1.Introduction

The study was qualitative in design, but a small contribution was made through the collection of quantitative data, and these results are presented briefly before turning to the qualitative data. The qualitative results are divided into two core themes (table 4): the first theme relates to shadowing as an activity, what was observed by participants, and how shadowers felt before and during shadowing. These results are presented in this chapter. The second theme relates to the changes brought about by the experience of shadowing, the knowledge and understanding gained, the emotions it evoked, and the impact on the shadower, and these results are presented in the next chapter (chapter 5).

Table 4: Themes and subthemes

Theme →	Sub theme→	Sub theme →	Sub theme
Shadowing as an activity (Chapter 4)	Observations made	• Physical environment • Relational care	
	Shadowing dying patients		
	Feelings about doing shadowing	• Anxiety	• about intruding • about what colleagues would think • about seeing poor care
		• Curiosity “give it a go”	
		• Doubt/uncertainty	• about how to do it • about learning anything
		• Shadowing dying patients	
	Feelings during shadowing	• Positive/enjoyment	
		• Uncomfortable	• out of role’ /personal professional split • being judged by colleagues ‘slacking off’ • sad situation
	Perceived impact on those being shadowed	• Colleagues • Patients • Relatives	

Responses to the experience of shadowing (Chapter 5)	Shadowing style	• Intervening • Mindful "in the zone" • Companion	
	How change came about	• Increase in knowledge and understanding (cognitive empathy) • Increase in affective empathy	
	Personal impact	• Motivation	• to make improvements for patients • re-engagement with own work
		• Thoughts about own dying, death and mortality	
	Shadowers' reflection on the approach		
	Subjectivity of observation	• 'Lens' affecting interpretation	• Personal experience • Professional experience • Personality
		• Emotional response affecting interpretation	

4.2. Before and after shadowing: survey results

A questionnaire was administered to all programme participants to assess attitudes to shadowing, and confidence in shadowing before and after the programme began. It was also intended to assess how confident programme participants felt that they understood the experience of patients and families, and how they rated their own empathy for patients, before and after the programme. Although there was a high response rate, with 42 (82%) pre-, and 33 (72%) post- questionnaires completed, only fifteen of the same respondents completed both pre-and post- questionnaires, so results from these 15 serve only to be taken as an illustration of how knowledge and attitudes changed (see methods chapter). Among these fifteen respondents, seven had done shadowing and eight had not.

Although statistical tests were not carried out, descriptive statistics show that of those who shadowed, the experience appeared to increase positive attitudes and feelings about shadowing, and to increased confidence in shadowing as an improvement method. Positive attitudes about shadowing moved from 40% of respondents beforehand to 67% afterwards. Overall, confidence in shadowing moved to 73% who said it was 'good' or 'very good' at the end of the programme, compared with 60% who said they had 'very little' or 'little' confidence beforehand.

Knowledge and understanding of patients' experience increased from 'very little' or 'little' in 73% of respondents at the start to 'good' or 'very good' in 80% of respondents at the end of the programme. However, the increase in knowledge and understanding of patients' experience was reported by fewer respondents who had shadowed (4 out of 7), than by those who had not shadowed (7 out of 8). It is possible that for those who shadowed there was a realisation that they had not understood patients' experience as much as they originally thought they had. This is borne out by the qualitative data, where participants spoke about 'eye-opening' and may explain results for self-reported empathy where there was minimal change in mean scores before and after the programme (14.27 beforehand (out of a possible maximum score of 20) compared with 14.73 afterwards).

4.3.Qualitative results

The remainder of this chapter presents findings from the qualitative data. Results are presented that pertain to the activity of shadowing. Until now, there have been no research studies which have given a detailed account of how shadowing is undertaken. In general, as revealed in the literature review, this is a failing of many published studies of projects to improve the quality of services. This section brings to light specifically how participants in this study undertook shadowing. The section begins with examples of the types of observations made about the environment of care by the participants. It then examines how the participants felt about undertaking shadowing before they started, and how this changed as they did the shadowing. Distinct from this, it explores the emotions evoked for the shadowers by being with patients in this way, and patients at end of life in particular. Speculation about how those being shadowed might have thought or felt about it is included. Finally how the participants went about shadowing is described in terms of the different styles adopted.

4.3.1. Observations on the environment of care

The participants, with diverse professional backgrounds, shadowed in varied settings: the project teams were in hospitals, primary care, a community and mental health trust, and a residential nursing home. They carried out shadowing for varying lengths of time, ranging from one session of half an hour to seven sessions of over one hour each. They shadowed at different times of day from early morning to late evening. Project team members in each organisation would meet and compare their notes afterwards, share what they had observed, and suggest ideas for improvement. The team debrief was important because participants had shadowed at different times in different situations, and so needed to be cautious before agreeing suggestions and action for making changes. Sometimes the same patient had been shadowed by different participants at different times of day, and it was valuable to compare their different reactions and reflections, indicating that a 'snapshot' cannot necessarily be taken to illustrate a typical experience:

> *And we had one* [shadower] *explaining that he was…you know, this poor person was lonely and had no interactions, just felt he was completely excluded from life and the world. And the other person was commenting on how it was lovely how the nurse sat with him and did her notes next to him and if he was a bit agitated she just stroked his hand.* [P6, clinician]

Others realised that during their time shadowing they were seeing only part of the experience and were cautious not to make generalisations about a complete experience from this; those who shadowed for some time and covered more than one shift could observe the contrast experienced by the patient at different times of day:

> *Sometimes it changed from shift to shift and I did wonder that afterwards, I saw a very small snapshot, that maybe it did change depending who the staff was. And I think sometimes maybe staff don't realise that, how pivotal their role is in that*

> *respect…..later on someone else comes on shift who's very good at what they do but perhaps doesn't have the same empathy and that's almost a bit sad for [the patient].* [P5, non clinician]

The purpose of shadowing was to gather information about the current experience of patients and families. This example illustrates not only the material differences in what was observed but the possibility of variability in the shadower's interpretation and judgements made, whether unconscious or conscious and this is discussed further elsewhere (chapter 5). With these caveats in mind, important themes about observations made by participants are presented.

Observations made by participants about the environment of care fell broadly into two categories: the physical environment; and the relational care, in other words how they saw people relating to each other. This relates to the definition of patient-centred care (see chapter 2, p.32) with components which are transactional, for example relating to physical comfort or privacy, and relational, for example communication, emotional support and relieving fear and anxiety.

The physical environment

Participants noticed different aspects of the physical environment which they had not until then been as aware of: how it looked, sounded, smelled or felt. At one hospital where a number of staff members had shadowed, and then discussed the notes they took, there was a shared reaction to how the physical environment itself looked, and its shabbiness:

> *…..the state of the wallpaper, or you know, you're looking around, you look around at these peeling walls, or dripping bits.* [P6, clinician]

As well as this, when they sat still for some length of time, participants were struck by the lack of visual stimulation for patients and families in hospital side rooms:

> *..but there's nothing…if you were to sit in bed not being able to do anything you want, something to engage yourself, you know, posters or clocks or something to read….So, that's what people came out with, that there was just literally nothing to look at.* [P6, clinician]

The bare state of the room was noted in a care home, but here the participant became aware more of the impersonal nature of the room and described it as an absence of 'homeliness':

> *This particular resident hadn't ..no real family, no friends that come to see her, the room was kind of sparse.* [P10, Healthcare assistant]

Several others noted that while there may not have been anything pleasant or distracting in the hospital environment, there was often unnecessary 'hospital clutter' and that this was not pleasing to look at, as well as inconvenient for the patient and family:

> *So, you've got this little table which is piled up with 101 things and you try and come and put your meal on it and that clutter gets put on the bed, or put into here, and no wonder things are lost. And there's a nebuliser machine, but they don't have a nebuliser, so why is it there, or why has the tray been put on the thing. They can't eat, so why are you putting that there? Or the oxygen masks, or the …all the hospital clutter.* [P6, clinician]

Participants noticed other details about the patients' immediate environment, which they felt indicated a lack of thought or awareness for patients. These could be small, practical things, such as a drink being out of reach amongst the general clutter, or difficulties with reaching the call bell, which they felt could be easily put right:

> *The one thing I did notice is his call bell was out of reach. And I mentioned that to him and he said, yeah, it keeps falling on the floor. And we're part of a new build hospital,*

> *PFI building, and when I looked, there was no clip on his call bell to keep it in place. You normally clip it to a pillow, but it was just hanging on the floor.*[P3, clinician]

A recurring theme, talked about by many participants, was how in particular the environment looked or felt for patients who were at the end of life, either in side rooms or single rooms, or on a ward in bays, and often made comparisons between the two. Describing the side rooms a participant commented that "*the rooms are very drab and they're very, yeah, depressing",* but went on to acknowledge that they were more private than the bays on the ward, where *"for the family members, you are in a confined space and you have these nasty blue curtains around, and you can hear everything else going on, you know, it's not quite what you need."* [P11, OT assistant]

Lack of privacy was a common theme, mainly in relation to what could be heard: another illustration was given at a different hospital where strangers could hear intimate conversations taking place on the ward:

> *When the doctor's going round to speak, you know, by tiny curtains which we all know, but it's a bit more brought to life when you're sitting there* [shadowing] *like a relative.* [The doctor]*is talking about their bowels, or whatever it is, and they're deaf so you're having to speak quite loudly, and then, of course the whole bay knows about this person's bowels you know? And even, you know it gets to the point where someone else's relative says, oh, I know he went yesterday, and like, what world is it okay where that person's daughter knows that this person had his bowels open yesterday? A complete stranger.* [P6, clinician]

Another participant realised that they could hear nurses talking by the reception desk during handover, with all the patient's personal information. This was something they had not been aware of before and illustrates how when sitting still and quietly alongside the patient, in a way they did not when working, they noticed things about the environment, like sounds, for the first time. This same participant gave the example of hospital bins:

> *The noises are different. I'm quite used to hospital environments, so noises don't tend to bother me, but when I was…as I sat there a bin went in the next…and I was like, oh, what's that?* [P6, clinician]

Another example of noticing how conversation and noise would be experienced by patients was given in a care home environment, where a participant shadowing in a single room became acutely aware of extraneous noise. She described the sound of hoovering outside the room, which she felt was intrusive. Then, after she intervened to stop it, and the noise outside the room had finished, she noticed the sound of her colleagues walking past:

> *You need to be respectful when you're going past that section of the house, not to be, you know all jovial and laughing and what have you. …yeah, you don't want to be laughing and joking down the corridor when someone's at the end of life.* [P10, HCA]

In a quiet side room in hospital, with the door propped open, a participant began to notice the noise made by other patients, which he found difficult and reflected could have been distressing for the patient he was with:

> *And then there was another patient, I think a couple of doors down the corridor who was quite noisy and probably a bit delirious or had dementia, so he was you know..a bit upsetting, a bit disturbing to hear him.* [P4, clinician]

Music being played on some wards provoked a variety of comments, which more than observations about other aspects of the environment, were expressed as personal opinions, probably because taste in music is particularly subjective. One participant felt that it would not be what the patients would normally listen to:

> *Sometimes they do have the radio on, on real, not appropriate music stations….just something like Kiss FM, something like that, you know, not music that our patients would probably be into in all honesty*. [P11, OT assistant]

The same participant judged a different ward to have 'nice music' on. In a different hospital the participant observed that although the music was not to her taste, she could understand why it was there:

> *There was music playing and I thought about how I would feel if I was a patient there. It was something like Magic FM and I thought how that would drive me crazy. It's very middle of the road but on the other hand it was quite quiet, it was only in the background, but I think because most of the ladies in the bay were asleep it would have been deathly silent if there wasn't music.* [P7, non clinician]

As well as noise, participants were aware of their other senses, and the smell of the environment was noticed:

> *Smells and stuff like that, you really start to pick up on things, and it smelt really nice because obviously the domestics had been round and it did smell nice.* [P10, HCA]

This contrasted with the observation by a participant, a non-clinician who would not usually spend time on a ward and was taken aback by what she saw:

> *I observed a nurse coming out from behind a curtain with a poo in a tray, not covered, at mealtime, you know and it made me gag, which I know is quite funny.* [P18, non clinician]

Relational care

In addition to the descriptive observations of the physical environment, the nature of interactions between people was noted by participants and observations made about how the way staff communicated with patients and families was variable:

> *Various members of staff came and cared for the patient in various ways and I started to notice aspects of that…For example, whether people introduced themselves and things like that.* [P7, non clinician]

Participants commented on how the routine tasks carried out by healthcare staff were enhanced for patients if they were shown kindness. When personal care was being provided, shadowers stepped away but could still experience the interaction with the patient, by listening from the other side of the curtains drawn round the bed. For example, the care of a dying patient was described by a (non-clinical) participant as sensitive in the way that they communicated with him, and explained what they were doing, even though he was not able to respond:

> *And while I was there they came in – the man that I was shadowing – they actually came to turn him 'cause of the pressure ulcer, prevent pressure ulcers. They did that, and I just said, I'll obviously sit outside. But I could still hear, they were talking to him and they spoke throughout – what they were doing, why they were turning him and saying, we're just going to move you this way, we're just going to move you that way.* [P5, non clinician]

In contrast an example was given of how mouth care was provided:

> *I didn't like something I saw, a lady who was end of life, a student nurse came up and gave mouth care, well without saying hello, Mary or whatever, it's Sue here, I'm just going to do something…it was like, went up there, and got the swab thing and shoved it in.* [P2, non clinician]

Food, and the way it was provided, was a strong theme. For example, someone who shadowed several end of life patients talked about how the moments of contact when food or a drink was provided could play an important part in the patient's day:

> *I watched a healthcare assistant come in and ask if he wanted a drink, and made sure it was in reach. She was very caring, she had a little chat with him about would he like to sit out later on, because he was up earlier that morning and went back to bed, and he said he'll see how he feels*. [P3, clinician]

For patients at end of life who are not able to eat much solid food, or eat at all, mealtimes took on particular significance. It appeared that some support staff did not realise this; one participant reported that a patient's request for a small amount of food was unheeded. Another participant observed how the routine of bringing meals did not seem to change even though the patient in a side room was not able to respond or eat, suggesting that the task was being carried out without thought for the patient and the feelings of his son who was sitting with him, which made it appear insensitive:

> *And there was somebody who came to offer food which was a little strange in a way because she came in and almost said to the patient who was really not very responsive you know, what kind of food do you want, here's the menu…and I thought well, you know, didn't she know this man was dying and actually he wasn't responding in that way.* [P4, clinician]

There were fewer reported instances of relational care which were purely actions to provide comfort or reassurance (aside from a necessary task). However, an example was provided of how one particular nurse demonstrated care for a dying patient:

> *..this one day, she just popped into see the patient and she was just standing there, just stroking the patient's hair. And yeah, that was really lovely to see. And she would sing a, this…I can't even remember what song it was, but it was just like this very quiet little tune. And I thought that was really lovely to see.* [P11, OT assistant]

Generally, many noticed how there was little contact between patients and staff, and often used the word 'lonely' to describe how they imagined the patient might feel. This perception that patients were lonely, a theme picked up by several participants, can be construed in different ways, as an emotional or physical state (or both). There was a sense that a patient *felt* alone, which might have been more keenly felt because a patient was dying. An impression of isolation, both emotional and physical, for the patient was detected by participants. Participants commented on a lack of comforting words or touch. Although it has already been noted that side rooms could appear dull (in appearance and because they were cut off), observations about loneliness and isolation were also made about patients' experience in bays:

> *…despite even if you're in a bay, a hubbub of stuff going on, there wasn't touch, there wasn't connection, there wasn't…you felt like everything revolving around you and you sat there. It was, yes boredom, but more than boredom, emotional disconnect, and that you probably get no emotional stimulation, unless you're able to engage it yourself, and that literally, you know the nicest thing is when someone came and held a hand, or just straightened the covers, you know, just that touch, that human contact… It's really lonely.* [P6, clinician]

Boredom was another aspect of isolation or loneliness, and the word 'lonely' was used by participants related to the idea that patients went for long lengths of time when nothing happened and they had no interaction with a member of staff, or a visitor or a patient. This contrast between how busy it feels when working and the revelation that for patients time drags, was often repeated by participants:

> *One of the key things for him [*the patient in a bay] *was that the system was not in any way being dynamic in managing his care so nothing much was happening and that was quite obvious, so there were times when nothing was happening…a lot of the time actually.* [P1, non clinician]

One participant described a nurse colleague's experience of shadowing on a nightshift where this was felt acutely:

> *When she was working a night shift how the time flies like that. It feels like, you know, it feels like half an hour and your shift is over because you are so full on busy and she was shadowing the patients, how heavily the time lay you know, that it was very, very long, you know, periods of time with nothing happening, no sort of stimulus, you didn't even know what time of day it was, you know, all that kind of stuff, and you know she started to think of them lying there worrying, you know, about what was happening to them and all of that.* [P1, non clinician].

The patients could be aware of this contrast between their experience and that of the nurses and other staff. One participant told how one of the nurses came over and said to her and the patient she was shadowing:

> *"Oh I hope everything's going okay today, it's such a busy day isn't it? Everybody wants a piece of you and you're rushing here, rushing there and everything", and then off she went. And we looked at each other and we laughed. And she* [the patient] *said, "no it's not, it's actually quite boring because there's long, long time periods in between different bits".* [P18, non clinician]

The different environments of side rooms and wards was mentioned in relation to boredom. A shadower in a side room heard from the patient about his experience:

> *He said he spends a lot of time just looking out the windows and he was looking at the shape of the clouds and things like that, so …because their day is so long isn't it? …you just wouldn't imagine that… he was just looking at the shapes of the clouds and how they moved.* [P20, non clinician]

A simple practical issue could cause problems for patients in side rooms, emphasising their isolation. One end of life patient talked to the person shadowing her about feeling unable to ask for help to watch television:

> *…she likes to watch a programme, and it's a quiz programme. But she said there's not enough remote controls for the TVs on the ward and it means that she has to call a nurse, but the call bell's often out of reach and she can't get the nurse to put the telly on. And then she feels bad for disturbing them for a television programme, which is the only programme she likes to watch. So she sits there thinking, shall I call, the bell, should I, shouldn't I, I'd better not, it's only a TV programme, and everyone's so incredibly busy.* [P3, clinician]

Reflecting on this, and why the patient could not call out from her side room, the participant realised that she would not be heard even if she did call out because there was so much noise from confused patients and other call bells, "*and she'd have to wait for someone to come in…..So I thought how lonely that could possibly be".* [P3]

In contrast, one participant noticed how patients in bays were aware of each other, and were able to occupy themselves by noticing what was happening for other patients:

> *I noticed that they observe a lot. They observe the interactions between other patients and they're very…I've heard them say I'm a bit worried about that patient today 'cause they don't seem their normal self, so they know other patients more than they think you do. They watch other patients a lot and they watch that they're upset when their family member's left or whatever.* [P20, non clinician]

Patients also closely observed staff on the ward, and noticed their different moods or interactions with each other:

> *They notice the conversations between staff and they notice the facial expressions and the, oh, what's happening today, they see all of it, the raised eyebrows, everything*. [P20, non clinician]

Talking about the policy of putting dying patients in side rooms, a participant became convinced that it was better for them to be in a bay, so that they did have the company of other patients, and activity to watch:

> *People wanted to be in the bay because there was more stimulation, a nurse walking past, or you hear conversation, or you heard what the other person was up to, and actually being, you know, in a side room, unless you had family with you 24/7, you were isolated, you were shut off, how lonely…* [P6, clinician]

This participant felt that "*when someone was made end of life that they were removed from people's minds",* partly because they were put into a side room and partly because certain [clinical] observations are stopped and "*at least with obs you were having some kind of human contact".*

In a side room one participant noticed how the cleaner might come in when the patient was in the bathroom in order not to disturb him but that actually, *"sometimes patients get quite lonely and might want to chat to a cleaner"* [P3, clinician].

However, not all participants felt that a side room being quiet was a problem. Another participant spoke about the side room where he was shadowing as peaceful, in positive terms, as though he thought it was appropriate for a dying patient, and even suggested it could have been better if the door was closed:

> *It was quite peaceful, the door was open. The things of course you notice are the little things. Firstly, the door was jammed open by the waste bin..It did seem quite bizarre that in a hospital we hadn't got little wedges to put under the door to keep it propped open, that a great big waste bin was used…Was it peaceful for this patient? You know given that he was dying was this a quiet environment? Almost you could ask why was the door propped open?* [P4, clinician].

This section has provided examples of observations made by participants, which related to practical issues and to the manner in which care was given. These included examples where there may have been opportunity for improvement, and positive interactions from which others could learn. This is discussed further in chapter 5, whereas this chapter focuses on the experience of participants of 'doing' shadowing, their expectations about shadowing before they began, and how their attitudes to shadowing and feelings changed, or how as they undertook shadowing, they came to understand it better.

4.3.2. Initial attitudes to the idea of shadowing

When they had made the decision to volunteer to shadow, most of the shadowers had understood its purpose, but attitudes to shadowing before starting varied from the sceptical to the positive, including those who said they were intrigued or curious about the method. For example, a clinical staff member who was with patients on a daily basis voiced some doubt (later reconsidered) whether shadowing would achieve anything useful, or add to what she knew already about her patients' experience:

> *Initially I think I was sceptical, I must say. I think that I thought I knew what my patients' experience was. I've trained a long time, I've been there a long time, I see what the ups and downs and the problems are, and everything else, and I thought, I know what I want to change, I know what. And so I thought, what's shadowing going to add to what I already know? So I thought I wasn't sure how it was going to give me a different viewpoint.* [P6]

However, others spoke of feeling privileged to be able to have the opportunity to shadow, and described how they embraced the chance to see an aspect of service delivery "*through a different lens, not just a healthcare professional lens*" [P13,clinician]. Others were willing to "*give it a go*", or volunteered to shadow in the hope it would make a difference to patients' experience. One interviewee described how she was intrigued about the method, and being non-clinical, was curious to see what happened on the wards. Another interviewee who worked in the quality improvement team said, "*I'm always interested in various quality things, and when a note came round on our intranet about this I thought it sounded interesting*".

Finally, a few participants were not sure what the process of shadowing would involve, or how it would work. For example, there were those who described themselves as 'doers' and felt they would not have the patience to sit still "not doing anything", and another who said she was a 'shy person' and was not sure how she would interact with patients and families. Thus personality played a part in how they felt beforehand:

> *I felt nervous because I'm not very good socially and I was a bit concerned that yes, I would be awkward talking to someone.* [P7,non clinician]

One non-clinician (a commissioner) was less confident about being with patients, or even nervous, anticipating that she would be expected to understand clinical conversations:

> *I have to say that I was very nervous when we agreed that we were going to do the shadowing… I felt that I was kind of on the back foot before I'd started, because they could enter into clinical discussions with the staff, whereby I'm non-clinical and so I felt that I'd be at a disadvantage.* [P8]

Professional background appeared to have an influence on now they viewed the experience, with clinicians feeling more confident on the one hand, about being with patients in the clinical environment, but at the same time, awkward about not being able to play their clinical role. One clinician was concerned about how she would go about shadowing, particularly how they would explain their presence to the patients and their relatives, as purely an observer:

> *So, before I went in there, I just thought, you know, I'll tell them about the project, tell them about my aim, tell them I'm not there to hinder care, but actually support and learn from it. And obviously, if they said they didn't want to be part of it, then, you know, to leave it at that and wish them well.*

These comments showed that staff were uncomfortable about being out of their usual role, and that this applied to clinicians and non-clinicians alike. In spite of the willingness to "*give it a go*" before it began, the most often cited emotions before shadowing began were apprehension, anxiety or worry. The reasons for this appeared to fall into three main themes: worry about being intrusive, how their colleagues would feel, and fear of seeing poor care.

Concern about intrusion

> *Were they happy with it? Were they aware? And was I ..I almost felt a little bit was I going to get in the way?* [P5, non clinician]

Several shadowers described being anxious beforehand, most commonly because of a concern about being intrusive or unwelcome, which as the quote from this participants illustrates seemed to be as much about their own feelings as concern for the patient. There was a sense that, even though consent was sought in advance from patients or their families, that in the event the shadower might not be welcome, as well as an anxiety that the patient might not in fact be 'happy' about being shadowed. Another participant described how she felt before she started shadowing:

> *It felt, although I think it's important, I think I felt it was quite intrusive and I didn't want to put anybody in a difficult position and I didn't want to be put in a difficult position and, you know, the nature of the care is quite intimate and, you know, it's uncomfortable*. [P1, non clinician]

There was a reluctance from one hospice community team to shadow in patients' homes because they felt this was putting the patients in a situation where they had no chance to opt for privacy, which they perceived was possible when curtains are drawn around a patient's bed:

> *We felt uncomfortable about going behind the curtain, as it were. And in people's homes that's what you do constantly, there is no 'outside the curtain'. So the public, private split was very, wasn't there really.* [P14, clinician]

This suggests that there was an unease for professionals about being outside the familiar hospice environment where they had overall responsibility, and in a patient's home where they felt they were a guest. This contrasted with a team who had been looking after patients with learning disabilities in their homes for some years and were comfortable with spending time with them and their families at home.

Another team decided not to undertake shadowing, and one of them explained it was because of the sensitive nature of looking after patients at end of life. Staff in this team said they would be reluctant to be shadowed, or shadow colleagues when having difficult conversations with patients, so their team leader took the decision to focus the project on supporting staff with these conversations, before undertaking any shadowing:

> *So the first year of the project was really about getting the staff on board with being able to have compassionate, courageous, confident conversations about advance care planning.* [P12, clinician]

Concern about how colleagues would feel

One senior nurse expressed anxiety about the intrusion for other colleagues, that they might feel that she was there to watch them and be critical:

> *There's a lot of pressure on nurses and staff on wards, and I suspect, I worry, as a nurse specialist, they might see me there as a senior member of staff come to make sure they do things in quite the right way*. [P19]

There was particular concern about the impact shadowing might have on social care colleagues:

> *In particular I think social care feels very observed in a very punitive way, and there was a fear that we were coming in to judge them*. [P14, clinician]

For some the anxiety was such that they took the decision not to shadow (as with this example in social care). One programme participant who decided not to shadow remembered being shadowed herself which she had found "*nerve racking*", and therefore was worried about other staff feeling the same.

Concern about seeing poor care

Fear of seeing poor care was an issue for a few participants, expressed in a number of ways. An occupational therapy assistant said she was nervous beforehand that she would see poor care: *"I was a little bit concerned at first because I kind of knew I wouldn't like what I was going to see*" [P11]. A nurse member of a team (in a joint health and social care service) where they had decided not to shadow, echoed this idea that healthcare staff would be anxious about seeing poor care, when visiting patients at home. She put this in the context of her team feeling powerless; she perceived that shadowing would be a negative experience for her colleagues if they were not able to do anything about making changes for patients. This suggests that joint working arrangements, and clarity about roles and responsibilities between health and social care needed to be in place before shadowing, and subsequent service improvement could be undertaken.

A programme coach also recognised that staff may have been reluctant to undertake shadowing because they were anxious about what they might see, but she thought this was for subtler reasons, that they were fearful it would upset their own equilibrium:

> *You know, when we started doing the Friends and Family Test, staff were absolutely petrified that it was just going to be critical feedback all the time from patients. So maybe staff have this fantasy that it's much worse than they think, you know, so they're really afraid of finding out how bad it is…And they don't want to, they really don't want to because it might upset their whole experience, you know, their whole work satisfaction I think.* [P16, clinician]

For the majority of programme participants, when reflecting afterwards, their initial anxieties and fears about shadowing had been unfounded. For example, a participant who had thought it would be difficult to 'do nothing' found the time went more quickly than expected. There was one exception, who said *"I was apprehensive about it and I found it quite an uncomfortable experience but I did it"* [P1, non-clinician]. Several others spoke of finding the experience less awkward or intrusive, than they had feared:

> *I thought this is quite a private thing for someone, that they're dying. And I did worry a little bit before I did it that maybe they didn't want someone here or that this wasn't something… but I didn't feel that…I didn't feel like I was intruding.* [P5, non clinician]

Participants, predominantly those with a clinical background, were concerned beforehand about how their colleagues might feel about being observed, particularly that they might feel they were being judged. However, in the event, when describing their shadowing experience, participants described how the opposite had happened, and that they had felt some discomfort and even that they were being judged by busy colleagues who might have been thinking they were "*doing nothing*".

'It's what you think other people think….[that] *it's not proper work*"[P16 clinician].
Despite the purpose of shadowing being explained, some participants were acutely aware that there might be a negative attitude towards the activity, as it might be mistaken for "*slacking off*":

> *I just imagine how the nurses are looking at me and thinking, she's doing nothing. It's what you think other people are thinking of you ….You know, there's this silly thing that goes on about how busy and how do you compare yourself in busyness? But that does play a part in what you're doing and what you're seen to be doing, too.* [P16, clinician]

Shadowing appeared to be easier for non-clinical shadowers. One who had said that she felt rather self-conscious initially, remarked on how she felt staff soon forgot she was there.

Teams had agreed beforehand that any examples of poor care would be reported immediately, and one example was given by a participant who reported a lack of communication, or poor communication with patients or families. However, more often participants observed care as good and indeed expressed corresponding relief. It was suggested by one participant that it would be constructive to go into shadowing with an open mind or even to look for positive examples:

> *A lot of people said "Oh I'm gonna find a lot of negatives" – when you go into the room don't assume that you're gonna find lots of negatives about things, try and find the positives as well. A lot of people are always looking for the negatives in life, but look for them positives 'cause they are there. It's the little things as well.* [P10, HCA]

4.3.3. Feelings during shadowing

For those teams who decided to go ahead with shadowing, it was recognised by some that it might be a challenging emotional experience and in some cases, project leads considered whether support might be needed for shadowers, in case they became distressed. One team leader described how this was discussed:

> *I wanted to open it [shadowing] up to people who I thought were going to have more insight, the students, the medical students or the nursing students, or the work experience people, or the porters or the …people who didn't work and live and breathe in a hospital so much. So there was talk about …do we have to offer support then, or can…you know, what kind of ..if it gets quite emotional who's going to be there to pick up the pieces at the end?* [P6, clinician]

In this hospital, preparation for shadowing included the project lead allocating shadowers to someone who was'right' for them to shadow. The example provided was where a 16 year old on work experience with the team shadowed a patient chosen by the project lead for her to shadow who 'wasn't so distressing'. The project lead made sure she was available on the day to support the shadower if needed.

Once the shadowing began, some respondents described how strong emotional responses were evoked via the experience of shadowing situations with patients in this way, particularly if they witnessed things they found difficult. A non-clinical shadower gave a graphic example of witnessing something that upset her, nevertheless emphasising the value of seeing it:

> *You witness things that perhaps you shouldn't witness. And one thing I remember particularly was I stepped outside the ward environment, just out of the bay, when the nurses wanted to do some of the personal care for this man and, you know, he was wearing incontinence pads and they were sorting all that out and I remember them, you know the curtains were obviously around and it was all private. But, you know, they sort of, took the old one off him and, sort of, slung it on the floor next to the bed*

> *and it was visible below the curtain and I found that really awful…but I also thought it was a really valuable kind of eye opener. That's the point really, isn't it, you know?* [P1]

The participant also reflected that although she was embarrassed, the patient might not have been at all, because she felt he was 'institutionalised' and no longer noticed indignities in his care. Another shadower described an example of a different kind of difficult emotion. She observed an advance care planning conversation about end of life, between a care home resident and her family, and a member of staff. She described how the interaction affected her in a powerful way emotionally: "*It's a very emotive subject and it was difficult to watch….it was very moving to watch….It was difficult for me yes, although I managed to keep myself in check."* [P8,non clinician]

Some felt anger and frustration. Describing a particular patient and how she felt when shadowing her, one respondent revealed how they connected emotionally, and she became involved in the struggle of the patient, and the frustration of wanting to help her:

> *I felt frustrated that she couldn't call her call bell, that she didn't have a remote control and that, you know, all she wants was a little meal occasionally, and we can't even supply her with that in a lovely big state-of-the-art building. What are we doing wrong to be able to not attend the patient's basic needs?* [P3, clinician]

Another shadower described her indignation when she witnessed the experience of family members, in contrast to a staff member, when visiting their dying relative:

> *So the room, oh, it disgusted me. So the room is hot in that ward, you know, it's very dull, it's very awful, the environment. The family were sat on these ridiculous plastic chairs. Bear in mind, they'd been with the patient all night….And there was a fan by the ward clerk and the fan wasn't on. And so the ward clerk kind of commented, saying, well, you know, that's my fan. And we were like, okay, right. [Her] attitude appeared unfriendly and uncaring.* [P11, OT assistant]

One person talked about the experience of shadowing being upsetting, and appeared to identify with the families of the patients she was shadowing, through imagining they were her own family:

> *It was quite an upsetting experience at times, because you always think, or I always think, you know, of my family members. If that was my family member, what would I want and how would I want people to react, you know. And yeah, it was quite sad and upsetting at times.* [P11, OT assistant]

When reflecting on her experience of shadowing a stranger, one participant used the word 'pure', and went on to illustrate how it can feel personally challenging when sensing the emotions the patient might be feeling:

> *It's quite pure really and you just cross that line into the real world of being a patient and it is actually quite frightening I think, I really do. I think it's quite daunting. But, you know, you can feel the vulnerability, I suppose of the illness, but also the whole situation of how much everything's hit and miss when you're in a hospital* [P16, clinician]

When they reflected on the time they had spent shadowing, and the impact it had on them personally, many participants spoke about it positively. A non-clinician spoke of the experience as 'lovely' and rewarding, because of the quality of the relational care she observed, which she felt was kind and compassionate:

> *Yeah it was a lovely experience. And I didn't think I would say that, it's a strange word to use when you're in a situation where someone is dying, but it was very comforting and I did feel that as a relative I would feel comforted…there was something cathartic, there was something about it that made it…that I felt okay about and good about after I came away. I felt quite honoured…to be part of it…being able to be just be a small part of something that actually might make a tiny bit of difference.*[P5, non clinician]

Others spoke of enjoyment and that the experience of shadowing was a privilege:

> *You do feel that it’s almost a nice thing to do. So you do feel that actually, to have that luxury of just being able to sit and watch somebody or talk to somebody or whatever*. [P20, non-clinician]

A senior doctor, after some hesitation, chose the word ‘unusual’ to describe the experience:

> ...*watching and listening and not doing anything, which is of course strange and a bit unusual…normally of course one goes to see a patient and talks to them and this was not happening in this situation so it was an unusual situation.* [P4, clinician]

For clinicians, being in an unusual situation with patients was at the heart of the experience of shadowing. One spoke about how the patient, or a moment had ‘stayed with them’, in a way that is different from meeting patients under other circumstances: *“It goes into a part of your brain that you remember what you’ve seen.“* [P11, OT assistant]

> *I can very distinctly remember certain aspects of that hour in a way that I might find extremely difficult to think about, you know, Mrs Brown or Mr Smith or whatever, who I may have seen in a clinic three months ago. This was a very different experience for me.* [P4, clinician]

One participant reflected *“I think it took the professional side of it away and brought the emotional side in”.* It was hard for some to let this happen, or if they did step out of role, found it hard. One participant [P16] reflected on how some staff were reluctant to shadow, or allow others to shadow their patients, referring to the concept of a boundary that has to be crossed in order to try to feel as their patients do:

> *“…crossing that line between being a paid member of staff who comes in and does a day’s work, to actually the patient experience. I think sometimes the people who are most protective of ‘my patients’, that’s their boundary almost, that protectiveness…I think it does come from the fear, and about crossing the boundary.* [P16]

This participant felt that crossing the boundary also meant relinquishing control and power:

> *You have to take off your member of staff hat. That hat, as a member of staff, has a power and a control to it that you have to let go...And if you truly do that, it makes you realise what a powerful hat we put on that people aren't even conscious of. [16]*

This concept touches on issues of professional detachment and unconscious defences which are in place (discussed further in Chapter 6). The support that was put in place by project leaders for their team is important in case the experience of shadowing is distressing. However, the subtlety of the emotional reactions might not be fully appreciated: these may be feelings of being uncomfortable, or awkward because of being out of the comfort of their professional roles. These findings present implications for how participants are supported and prepared for shadowing (see Chapter 6).

4.3.4. Shadowing dying patients – a special challenge?

The Point of Care Foundation's manager for the Living Well programme described how shadowing had been undertaken with other patient groups in previous programmes, but when the approach was first suggested in end of life care, she had some concern that it might not be acceptable to programme participants, that there might be reluctance to shadow or that they would feel it was inappropriate with this group of patients. This was illustrated by two participants in the study who focused on ethical issues associated with their projects, specifically in relation to consent. Gaining consent from patients to shadow them was not always possible, if they were confused or not conscious for example, and there was a small indication that this made shadowers feel slightly uneasy, although they were able to justify it to themselves:

> *But I suppose I would reframe that as to what you're actually consenting to is to understand the environment, not understanding their experience because you can't talk to them, but you're understanding the environment that you are sharing with them.* [P14, clinician]

An example of this was given:

> *I wasn't able to seek this patient's permission, I suppose I'm just thinking about that, and I suppose that is the case, really people are going to get very weak, and do get very weak, particularly at the end of life. But yes that sense of the environment in which one is caring for somebody, is it the right environment for them? How can we improve on that environment both in terms of the physical nature of the environment and also the interactions with staff that are going on.* [P4, clinician]

Thus, in practice worries about consent were allayed because the shadowers were understood to be observing the environment of care for the patient, and those who were able to communicate were given the option of saying no to being shadowed.

At first there was indeed some reluctance to shadow, specifically related to patients being at the end of life, for reasons that were broader than practical or ethical concerns, and appeared to be more about the shadower's own uncomfortable feelings about being with a dying patient. The leader of a team which took the decision not to shadow, spoke about how staff in the team had been anxious about shadowing patients in single rooms, which they felt would make the experience too intense:

> *We have patients in single rooms here and I think some of the people that perhaps we would have chosen to have observed, it just felt like it might have been quite….I think staff were anxious, you know, being in a room with somebody that was dying, with the family, and for a prolonged period of time and the logistics you know of how they would actually do that. It's not like sitting on a big ward, you know, observing lots of different things*.[P12, clinician]

A member of another team, from a hospice, where they had decided not to shadow, reflected about whether shadowing dying patients was different from shadowing others:

> *The question is should you be more careful than anywhere else? I think it's about reverencing a person and ..perhaps at end of life emotions may be nearer the surface, there may be more distress*. [P12, clinician]

The fact that patients were near the end of life appeared to increase this anxiety for some participants, for different reasons, depending on their role. Although a healthcare assistant said "*obviously you do look after people at the end of their life. So, I had seen patients at the end of life before, so that didn't scare me as such".* Among clinicians there appeared to be concern that their non-clinical colleagues who did not work with patients might find the experience of being with dying patients distressing. In a residential home setting, shadowing was undertaken by commissioners from the CCG who witnessed conversations about advance care planning. One, with a clinical background said of her non-clinical colleague "*obviously [she] not being a clinical background, struggled initially. I didn't, because my background is clinical*". Emotional support was put in place for non-clinical colleagues but the one clear example where support was taken up was by a clinical participant: a team leader in community health described providing support for her team of nurses, including one who found it upsetting to discover that the patient with learning disabilities she shadowed (between home and hospital) had not been identified as needing end of life care until it was too late.

However, the anxiety from clinicians and non-clinicians alike was chiefly about whether it was appropriate to intrude at a private time, when there may have been only a few days left for the patient. A senior palliative specialist who now advocates shadowing explained her initial anxiety:

> *I worried about invading people when time is short. I think I was thinking about it at that time very much around the last few days of life….And I think sometimes that time is so precious for patients and families that they don't want an observer there.* [P19, clinician]

Some brought their own personal experience which influenced their concern about being an unwanted presence:

> *And I only recently lost my father, over the last year, I thought how would I feel having someone else in the room, watching what's going on, at the end of my dad's life. I'm not sure how comfortable I would have been.* [P3, clinician]

A shadower who was with a dying patient and his son, was aware of the sensitivities in the particular situation he shared with them, and reflected afterwards that it had felt a little difficult:

> *It just felt a little bit difficult, not strained at all, but just unusual to be sitting in that space, watching what was quite an intimate inter-reaction between the son and the father, clearly the son understanding that his father was dying, you know it's obviously a very personal, emotional experience*. [P4, clinician]

But in terms of their own emotional responses, some reacted to the situation that the families were in. One participant saw a conversation between the patient and her family, and a member of staff:

> *The nieces started to get a little bit upset, and that was really difficult because this lady has no other family, they've been looking after her for a number of years… and it must be very difficult to be a close family relative discussing such things, and it's hard, it's hard*. [P8, non clinician, commissioner]

A therapy assistant felt the family's emotions acutely:

> *To them, it's like their life is about to, you know, fall apart because their loved one, who was this massive thing in their life …to their family member, they're their life, you know.* [P11]

A participant who had her own recent experience of bereavement talked about how this definitely heightened her emotional response:

> *I think having the experience I had as well at the time, it was kind of like, yes, had a big impact on me* [personally and professionally]. [P17, clinician]

For some the experience had a profound personal effect on them, and they spoke in thoughtful terms about its impact, with thoughts about their own mortality, death and dying:

> *The fact that there was someone that was there that probably was going to die very soon I think made me…I came away reflecting perhaps..it gave me a slight, you know, that life is life and sometimes we spend too much time worrying about things that you don't need to worry about.* [P5, non clinician]

For this participant the experience clearly stayed with her for some time afterwards, and affected her thinking in relation to her own life:

> *And since then I've looked back on the experience and I've kind of used it to – when I felt anxious about something that I can't do a lot about – to actually think about that time and think about how I felt and about how the people around me were feeling at that time.* [P5, non clinician]

Others did not reflect on the experience of shadowing in quite such a personal way, but for some, the impact extended to their family life in a practical way:

> *Whilst I'd made a will and I'd started talking to my daughter about if anything happens to me and her dad, I hadn't actually written anything down, but since this shadowing I've actually completed those [advance care plan] documents for both myself and my husband.* [P8, non clinician]

Another shadower described how she spoke about death with her young child:

> *…having conversations with my five year old, who's now got a concept that something happens, that people do die and having quite difficult conversations, and it linking with this. It made me think about it all more*. [P5, non clinician].

There was a perception that the shadowing process was positive for these patients and families, and participants felt that if they approached shadowing carefully shadowers could provide company and even comfort for the patient. This appeared to be personally rewarding. One shadower, a hospital volunteer, who said, "*I'm quite philosophical about death, it happens to all of us*", went on to talk about how her husband had died in the same hospital, and she had felt that she wanted to contribute to the project by volunteering to shadow dying patients, as a way of providing company for them at a time she felt that "*no-one should be on their own*", and that she was glad to do this.

One non clinical shadower spoke about how the experience of shadowing had benefited her in a personal way. After seeing her grandmother's poor experience of dying in hospital this participant talked about gaining reassurance that this was not the case for all patients. She had also described her grandfather dying at home, an environment which she described as "*too silent*":

> *I went home and talked about it to my husband and reflected that actually it had given me a different perspective on dying in a hospital. And maybe your own experiences can sort of cloud that judgement….it wasn't this awful thing if you like and actually it was a very calm place. I thought afterwards when I was reflecting on it, that actually because your hearing's one of the last things I think to go isn't it, that actually being able to hear the world around you could actually be quite, I'd like that. I'd think normal life was still there…I think the silence would be too much.* [P5]

This shadower went on to describe her experience of shadowing as comforting, even cathartic:

> *When I was reflecting on it afterwards, I thought, death is normal….it was a lovely experience. And I didn't think I would say that, it's a strange word to use when you're*

> *in a situation where someone is dying, but it was very comforting, and I did feel as a relative that I would feel comforted….There was something cathartic, I felt okay about it and good about it after I came away*. [P5]

In summary, it appears that anxiety before shadowing may have been intensified because patients were at the end of life. For example, fear of being intrusive was amplified by knowing that the patient may not have had much time left with their family, and that it was a private time. Some non-clinical staff were slightly apprehensive about being with patients who were dying, although in the event, the emotional support for them which was put in place was not needed. Clinical staff, including junior staff, were used to caring for patients at end of life and many, like their non-clinical colleagues, found the experience rewarding, giving them the chance to take time to reflect on patient care, and that it 'reconnected' them with patients and their own motivation to care. The project teams were encouraged to debrief together after shadowing, and this support, together with a sense of purpose and satisfaction when they discussed and made changes for patients, helped participants to understand the experience as worthwhile and rewarding. One junior member of staff described it as the same good feeling as when she did an activity to raise money for charity.

In spite of some doubts about how appropriate it was to shadow patients at end of life, one clinical participant concluded: "*I think there's perhaps a perception that it would be more difficult, but I don't think it was*".

4.3.5. "*I'm glad someone is taking an interest*": perceived impact on those being shadowed

While observing the environment they were in, and what was happening around them, some participants noticed how others reacted to their presence. They reflected on the responses of three different groups of people to being shadowed: other staff or colleagues; patients; family members.

Some participants were aware of how their colleagues were responding to their presence, and that it appeared that for some staff it was not easy. This was possibly felt more acutely where a more senior clinician was shadowing. A consultant doctor described how she thought her presence influenced her colleagues' behaviour:

> *We had some uncomfortable nurses who felt they were being watched. So that took managing because they felt we're there to criticise them, or their care….that was a recurring theme. So certainly when I was there the nurse was trying to tell me what she was doing with the patient and I'm like, I'm not here in that role…don't tell me what you're doing, and I think almost checked on my patient more than she would have because I was there*. [P6]

The same doctor went on to reflect that although the other staff knew that the exercise was to understand patients' experience of care, they interpreted it in a certain way, perhaps because she was there and this affected their behaviour:

> *…they were checking catheters, and things, and doing all the, you know checking, but actually no…but didn't hold his hand and say, are you okay. Isn't that funny, that's what they think I'll be measuring. But it didn't even cross their minds that the experience might include touch or feel or…They thought it meant measuring the urine, or whatever it was. So, although they got more attention I'm not sure it's attention I think I would have wanted if I was in that bed*. [P6]

Other participants also questioned whether their presence made a difference to how other staff behaved, and therefore whether they had gained a reliable impression. One described an interaction with a doctor:

> *I mean you can easily, I would imagine, upset people because you're sitting there..one doctor actually, when I was giving* [the ward manager] *some paperwork back, he said I saw you sitting down writing, what were you doing? …So yes, I'm sure you could easily upset people and I wonder sometimes do you always get the true picture.* [P2, non clinician]

However, another participant remarked on how she felt staff soon forgot she was there and behaved as they would normally:

> *As much as I was aware that they were aware of what I was doing, and I was only there for an hour, there was enough going on for them to perhaps forget that I was just there because I was just a visitor sitting there…I felt perhaps that I did just sort of fade into the background a bit in a good way.* [P5, non clinician]

A healthcare assistant described her colleague’s reaction to her shadowing, and both she and they appeared more relaxed about the activity. This may have been because the environment was a care home rather than a busy hospital ward:

> *One person did come past and go, what are you doing. I had* [the door] *ajar a little bit because I didn’t want…because our staff, they are nosy, they want to know what you’re doing here.* [P10]

There was a suggestion by one participant that the shadowing provided a service that the nurses did not have time for, and so colleagues were grateful that someone was able to sit with the patient:

> *The nurses are now so busy that they have very little time which was proven by doing the shadowing. So having someone sitting there, even if it’s part of a project I think would be reassuring as opposed to being awkward.* [P6, clinician]

A similar point was made by more than one participant, who felt that patients and families appreciated the interest that was being taken in them:

> *I think it benefits patients because I think they feel, you know, that somebody is interested in what’s happening to them and that the service cares about them and I think that’s a fantastic antidote to just feeling like a number, which is an issue.* [P1, non clinician]

When the time came, some patients were not awake or very responsive, but those who were able to respond appeared generally happy to be shadowed, and several participants commented on how they thought they welcomed the company, and appreciated the attention, and the organisation’s purpose to improve care. Others reported that they felt patients appreciated practical help, particularly if they did not have a family or other carers accompanying them to help to navigate services or help with small practical tasks like helping them to have a drink. Several participants reported that they were thanked by patients and relatives afterwards. A participant shadowing a patient at an outpatient appointment said she felt it was helpful for the patient, and that she was grateful for company:

> *She* [told me] *that she found it really nice that she had somebody with her during it. So actually there was an added benefit to the patient of just having somebody to chat to.* [P18, non clinician]

One exception was mentioned where the patient clearly did not welcome the shadower:

> *I’d been to him* [the patient] *and consented him, he said it’s all fine, it’s all great. By the time she* [the shadower] *got there in the afternoon he was really not very happy and told her to bugger off, and he was quite rude.* [P6, clinician]

Participants were always careful not to shadow if it was not welcome or difficult for a patient. This varied with circumstances: while a patient in outpatients might be glad of company throughout the process, a participant who was sitting with patients with COPD on a ward was aware that they found it tiring to have her there, and was careful not to outstay her welcome, or become a burden to them in any way.

In the same way that it was felt that patients appreciated the attention, participants thought that family members were positive about shadowing, once they understood its purpose, to improve care. For example, a participant described one family member’s reaction who had initially been unsure what the shadower was doing, but then reacted positively:

> *The son wasn't expecting me, and here I was, kind of observing him as well as his father…right at the end, I just, I got up, I said thank you…thank you very much for letting me sit in with you and your father...I hope I didn't distress you in any way. And he said no that was fine…I think he almost appreciated at the end of this time, having not expected me to be there, a sense that we were taking an interest, looking at it from the patient's perspective. So we shook hands and he was, you know, he said thank you very much for what you're doing.*[P4, clinician]

Another relative responded favourably once the project was explained, and suggested other areas of the hospital which would benefit. Others who were approached for permission to be shadowed were not against the idea, but the circumstances were not right, usually because they wanted time with their relative alone. One participant, who had shadowed the most patients at end of life, and in some cases their families, noticed a difference between different family members in how they felt about her shadowing; some were not comfortable, in which case she stepped away all together:

> *I think, without sounding sexist, I noticed that males found it more* [awkward]. *Because I think they obviously keep their emotions more, maybe, I don't know, whereas the women, the females, were fine. And I found, like, teenagers…found it a little bit difficult as well. But in cases like that, I kind of did say, look, I'll come back at another occasion, because I didn't want to put them in a position.* [P11, OT assistant]

This highlights the importance of explaining and gaining consent to shadow from each visitor.

4.4. Summary

This chapter has examined the emotions, expectations and attitudes expressed by participants about doing shadowing. Many expressed apprehension about shadowing before they started for a number of reasons, including a worry about being intrusive, anxiety about how their colleagues would feel about their presence, and concern about seeing poor care, but when they reflected about the experience afterwards these proved to be largely unfounded. Individual factors influenced the attitudes and expectations staff had about shadowing before they started, as well as the approach they took. Whether the shadower had a clinical background for example, or was non-clinical and not used to being with patients appeared to be important, but personal experience was also brought to shadowing, and influenced how they felt. Those who had a strong emotional response to being with patients and families at the end of life appeared to relate personally to them. The particular emotions and challenges associated with shadowing patients receiving end of life care are discussed: for some the experience and their reactions to it appeared to be intensified because the patients were at end of life.

These findings have implications for how shadowers are prepared before they begin shadowing. Anxieties can be addressed, and the approach to be adopted could be made clearer. Efforts need to be made to explain the purpose of shadowing activity to colleagues so that they understand they are not being monitored, and so that shadowers feel confident that they too are not being judged. It appears that once they have given consent patients and families appreciated the attention to their care experience. Support should be in place, which recognises that the challenge for shadowers is predominantly emotional, before, during and after shadowing, and that they will be in an unusual situation with patients (and colleagues) which while comfortable for many could make some feel awkward, regardless of whether they usually have a clinical or nonclinical role. Debriefing with others is important as a means of support, and to compare the different observations made about transactional and relational care. The shadowing experience was seen as valuable by those who undertook it, both personally and for the service.

CHAPTER 5: RESULTS (2)

The response to the experience of shadowing: how change came about

5.1. Introduction

The second results chapter explores the contribution shadowing might make to patient centred care, due to its impact on staff. It explores the response of participants to the experience, and begins with presenting the different styles that participants adopted to managed the task of shadowing. It then explores the responses they had to the experience in terms of increased understanding, and empathy, and how in turn their responses could bring about change for patients. ‘Work as imagined and work as done’ is a familiar concept in quality improvement projects which focus on patient safety, where the contrast between assumptions about procedures in healthcare are challenged by examining in detail what actually is done (Hawkes, 2013). The new understanding or knowledge about patient experience which came about through shadowing is demonstrated. The emotional response, and affective empathy are discussed next, which relates to how observations are necessarily subjective for different reasons. Motivation of participants to make change is included, and lastly the participants’ own reflections on how shadowing might make a difference to patient care.

5.2. How it was done – different styles of shadowing

Finally, a clear theme related to the activity of shadowing, was how participants adopted different styles and approaches. In spite of guidance, the way that individuals undertook shadowing appeared to depend on a combination of their personal and professional outlook, and their personality. The approach to shadowing fell broadly into three categories: where the shadower consciously tried to ‘get in the zone’ to imagine what it was like to be the patient, and did not intervene; where the shadower intervened in the care of the patient to a greater or lesser extent; and where the shadower acted as a companion to the patient. Occasionally more than one of these approaches might be adopted within one shadowing session, particularly where shadowers struggled with not intervening.

An example of the non-intervening approach, and of a conscious attempt to understand and feel what it was like to be the patient, was given by a healthcare assistant in a care home who had shadowed a resident in her room:

> *Yeah it was quite strange, I didn't think I'd get into the zone so quickly, and it was only within a couple of minutes and I was right there with her, and that surprised me. I thought, if I'm honest, I'm going to sit here , half an hour and just sit here, but do you know what I mean, I honestly just thought, what am I going to see, what am I going to hear, but within a few minutes, I'm like uh, it's a bit chilly, close the window. The noise, and even like smells and stuff like that, you really start to pick up on things….I felt that she felt comfortable. And that was nice…because you're putting yourself in their shoes, you kind of take the carer or the nurse hat off, and then you just become, you become part of them, and part of their environment.*.[P10]

This concept of getting "*into the zone*" was also described by a shadower who sat in a side room with a dying patient, when he described the experience in the following way:

> *Really it was just you know, an hour of almost like meditation in a sense, of watching and listening and not doing anything which is of course strange and a bit unusual.* [P4, clinician]

This was perhaps an example of someone who was able to approach shadowing in a similar way to meditation or mindfulness, just sitting with and being able to observe thoughts, feelings and sensations, which appears to be a skill that was not possessed by all participants. Another participant had spoken like this when reflecting on empathy and compassionate care: "*I think mindfulness...the ability to notice oneself has to come before the ability to notice the other*", and went on to say that she liked to use the word 'attuning' in relation to empathy and compassion:

> *Compassion, dignity, empathy, person-centred care – the word I use a lot is attuning, attuned care…attuning in the psychological, relational level of attuning to the reverence between people*.[P14, clinician]

There was an echo of this with a participant who worked with patients with learning disabilities who cannot speak, when she explained that she felt her approach to shadowing came easily because she was used to watching and "*tuning in*" to how they were feeling:

> *I was chatting to my colleagues, who are also community learning disability nurses, and I think we found the shadowing easier I suppose than some people might. I think because in our role often we're…having to pick up on a lot of the cues and things as well, it didn't feel unnatural to do the shadowing…So I guess it's a skill that you use that you're not always aware of.* [P17, clinician]

A programme coach observed how it might be that some personalities struggled with shadowing more than others, and compared it with mindfulness, increasingly taught to healthcare staff:

> *It's almost like actually people who can cope with mindfulness or meditation will find it easier. ...I wonder whether people who just can't sort of slow down and just be there, that's the trick, and that is actually quite a challenge. And it's something we're not very, human beings aren't very good at, and actually particularly carers in a healthcare setting, they're always 'doing'. So it's that as well, actually, and that shift into a more mindful, reflective state, and some people just never go there*.[P16]

Shadowers with a more intervening style tended to have a nursing, or healthcare assistant background. They tended to step in to care for the patient, either where they felt other staff were not doing their job properly, or because it was instinctive for them to care for the patient because of their professional role. Although clinicians were usually aware that they were supposed to step out of their professional role (in order to put themselves in the patient's place) they found it harder than non-clinicians to do so. One described how difficult it was for her as she was self-conscious, *"you're the elephant in the room aren't you really?"* [P9]. Some described how they were so used to being busy, or hard-pressed for time, that they found it very difficult to sit still, if they were shadowing a patient who was lying in bed. A doctor (consultant) said

> *…the idea of having to sit there…sitting there for an hour and not doing anything…because if I was sitting there and there's something going wrong I want to go and do something about it.* [P6]

A healthcare assistant in a residential home described shadowing a patient near the end of her life, and how she had intervened to make the physical environment better for them, which was her instinctive reaction to being with a patient:

> *The domestics had been in the room earlier on during the day, opened a window to let some breeze through and then the wind kind of picked up in the afternoon and I'm sat there and I thought it's a bit cold in here…Well if I'm cold, she must be really cold. So I pulled the window to and another blanket on her and them sort of things. Also there was...I heard someone outside hoovering and they kept going up and down the same corridor, like loads and I went, what are you doing hoovering?.....Once I explained myself and explained what was going on then she went and hoovered somewhere else, she took her hoover away.* [P10]

Those with a nursing background sometimes found it difficult to imagine the experience of care from the patient's or family's point of view and particularly noticed and commented on the clinical care provided. For example, one shadower described her experience of shadowing in terms of checking on the care provided, rather than attempting to understand the experience patients were having. The first patient she shadowed was asleep:

> *So I took that opportunity to go through his paperwork. I could see some gaps in documentation around basic nursing care….you could see in front of me that he'd been cleaned and washed, but nothing was documented.* [P3]

In other instances, it appeared to be hard for the shadower to remove their professional 'hat' to such an extent that they were focusing on and judging the way staff carried out their tasks, forgetting the purpose of shadowing was to understand the patients' experiences of care. After sitting in on an advance care plan conversation, a participant judged the nurse:

> *The nurse felt that she was confident to do it, and then when we started, didn't handle it particularly well…so the shadowing turned into doing some exercises with her.* [P9, clinician]

This contrasts with the non-intervening shadowers who were aware of noises in the environment for example, and even if they found them disturbing, merely noted them as part of the environment the patient was in. However, in one instance, an occupational therapy assistant described shadowing a patient in a '*miserable*' side room, traditionally kept dark during the day for dying patients, with the blinds drawn:

> *So the action I took was I went to sit and talk to the patient, because after a little while… I'm a talker, so I thought, do you know, the patient was opening his eyes and was kind of like trying to talk, you know, but couldn't see me at the time, and then yeah, so I opened the blind and let some light in, and I opened the door, you know, and turned the lights on.*[P11]

Other shadowers engaged patients in conversation, but tried not to intervene further:

> *…my particular role was to sit next to a patient … also look at the interactions with staff, and observe really, which for me, I found that quite hard at times because I'm a person that likes to jump in and get stuck into things and be more active.* [P20, non clinician]

One shadower described deliberately chatting to the patient in order to discover whether what she noticed as a shadower was aligned with what the patient was experiencing. [See next chapter which discusses shadowing 'through the patient's eyes].

This appeared to be an approach to shadowing planned purposefully within an improvement framework; the shadower wanted to be sure that the intended focus for their project was correct.

Those who saw themselves in the role of companion tended to be staff with non-clinical backgrounds. One shadower was a hospital volunteer, who wanted to help the project team with shadowing expressly to sit with dying patients as a companion:

> *I do have a thing about, I hate to see or think of people being on their own and having no-one. So, although I would be shadowing, I might well be holding someone's hand at the same time… I think it might have eased them, given them some comfort.* [P2]

A healthcare assistant mentioned how she responded to the patient she was shadowing: "*I think she knew I was there, I held her hand*". [P10]

Another distinguished shadowing from observation by saying

> *It's different from observation in that you sort of accompany the patient. You're with the patient…it's with them rather than observation of them. I think it feels more shared*.[P1, non clinician]

However, one participant was aware that patients might not want companionship for too long:

> *It's not very nice if you're a patient to have somebody just sat there watching you all the time. So I tried to be, move around a little bit and then come back to the bed and sit in an area that was slightly discreet, away from the patient, so they didn't feel I was watching over them all the time. I was very aware that I didn't want to…yeah, feel a burden to them in any way.. they could talk for a little bit and then after a while it became quite hard to talk*. [P19]

In conclusion, personal factors can be seen at work in the style of shadowing they adopted; some personalities found it difficult not to intervene in care as they accompanied patients, and others saw themselves as providing companionship, and enjoyed talking to patients. Others made themselves as invisible as possible, and made a conscious effort to 'get into the zone' to understand what the patient was experiencing. These different styles of shadowing appeared to reflect a combination of clinical or non-clinical professional background and personal outlook and experience.

5.3. Work as imagined and work as done: cognitive empathy

Empathy is the capacity to place oneself in another's position and to understand or feel what another person is experiencing within their frame of reference. Participants described how the activity of shadowing enabled this to varying degrees, and affected their feelings and understanding in ways which can be interpreted as relating to both cognitive empathy, which is how we understand other people, and to affective empathy, which is our emotional reactions to people (Baron-Cohen 2012; Halton and Cartwright 2018). Findings related to cognitive empathy are explored first. When reflecting on the experience of being with patients, participants did not use the word 'empathy' but talked about it increasing their knowledge or understanding of what the experience of patients and families was like. The benefit of taking time to step out of a normally busy day was mentioned by several participants:

> *I think the trouble is we trundle through, don't we, and do get caught up in just the doing, without stopping and thinking about what happens to people. So I think it just opens your eyes really. So I think it kind of takes the filters off a little bit, doesn't it, and you are much more aware on the wards and in the environments about what's going on for patients and families, and the noise of things and the sight of things* [P19, clinician].

There were some reflections from clinicians that it was particularly valuable for non-clinical colleagues to shadow because they did not have preconceived ideas and brought a fresh eye to it:

> *They ask that question about why we do things, but also they can come up with different ideas. And sometimes we do things because we've always done it that way*….[P3, clinician]

A quality improvement professional described how, having shadowed, she would recommend it to others in her team to help them with the understanding needed for their jobs:

> *I hadn't really understood just how important a tool it is, and I'd say it's a massive thing, and it gives you a completely different perspective to what you thought, what you had read on paper. But when you get the human factors come into it, and the way people are, and the life going on around, it isn't that simple.* [P5, non clinician].

A strong theme was how shadowing for clinicians and non-clinicians alike had the effect of challenging the status quo and encouraging change to happen:

> *It stops and makes you think. It makes you reassess what you're doing, and yes, basically what we're about.* [P17, clinician]

Some spoke of their surprise to discover how the experience of patients differed from what they expected and that previous assumptions were challenged by being forced to stay with the patient's experience. The phrase *"eye opener"* was used by six different participants:

> *It was incredibly boring and although we think we're busy, I mean I feel busy on the wards when I'm there as a doctor, you know, crazy busy. From a patient's point of view, you're lucky if you see a nurse, let alone be able to talk to a nurse or communicate to a nurse.* [P6, clinician]

At one hospital it was common practice to put a patient who was dying in a side room, but it came as a surprise to participants how the environment was possibly too quiet:

> *We all presumed, automatically we say, if someone's dying, you know, if we've got a side room we'll try and get you in there so you can have more privacy and everything else. Actually it was completely the opposite….and [we] actually completely changed our views about putting patients who are end of life into a side room.* [P6, clinician]

This was not only a subjective reaction on the part of the participant (albeit based on what patients indicated) but also arose from a new understanding, having seen how little interaction patients had with anyone else, particularly once they were put on an end of life pathway and observations (such as taking blood pressure) were stopped, which meant there was very little physical touch or comforting communication with the patients. This ward then changed its practice, so that the use of side rooms was considered more carefully.

Discovering that there was an inappropriate approach to providing meals for patients at the end of life; that privacy and confidentiality were not as secure as assumed; and that the environment was noisy, were other examples of gaining knowledge which helped to inform improvements that were then made to hospital processes. (See appendix H which provides documented examples of improvements made from the teams' project reports).

It was a surprise for a clinical participant, who had not stopped to sit in a bay before, to find out that there was such a lack of privacy:

> *It does make me think quite a lot about privacy and governance and confidentiality. You know, we're all big on it, but are we? Because everyone can hear about it, you're having an end of life discussion with someone and everyone knows in that bay you're going to die. That's quite…so that was surprising.* [P6, clinician]

In the community setting a nurse spoke about improving advance care planning with patients at end of life, including designing new training:

> *It meant I had to re-challenge, or at least re-focus, on the things that we do, and we all think we're experts and we don't need to do anything new…because sometimes we think we know what patients want or relatives want, and actually coming back to ground roots does kind of re-focus things.*

5.4. Emotional response and affective empathy

It has been claimed that shadowing can increase empathy (Shaw et al., 2014). This may have happened through both observing and learning from examples of care which demonstrated empathy, and through an emotional response to the situation or patient or family being shadowed. Some participants reflected on kind or 'lovely' relational care role modelled by colleagues, and how this had a positive impact on their own behaviour and thus on patients' experience, such as this participant who reflected on how they had learned through doing the shadowing, and with the benefit of hindsight might change their approach to care in some ways:

> *I think you learn a lot about yourself as well as about your patients as well and how you can make improvements to their care and the whole family situation just by spending that time observing, seeing things.* [P17, clinician]

Seeing poor care, which was unkind or thoughtless (and possibly showed lack of empathy) galvanised a response and a motivation to improve the experience for patients or families. The experience of shadowing a family visiting a dying relative illustrates how an emotional response caused action to be taken. The participant said "*Oh the room, it disgusted me",* because it was hot, and they had to sit all night on "*ridiculous plastic chairs".* This participant went on to say, that although she had always thought she was "*very sympathetic and stuff*", she now does more:

> *So if a patient is at end of life, I will say to them [staff], have you offered the family tea and coffee, have you offered this, have you done this, have you done that.* [P11, OT assistant]

This sense of the experience making an impact was described clearly by one shadower (a doctor) in terms of an effect on her as a person rather than a professional:

> *I think it took the professional side of it away and brought the emotional side in*. [P6].

Impact was demonstrated too when participants described how the patient stayed with them in a way that is different from meeting patients under other circumstances, and how they connected emotionally with particular patients or relatives they shadowed:

> *She looked very vulnerable and basically you wanted to scoop her up and take her away.* [P3, clinician]

None of the shadowers spoke explicitly in terms of feeling empathy, or used the word empathy. Even so, these emotional responses reveal how the participants' affective empathy with patients and families can be evoked by watching scenarios unfold when shadowing. For example, when expressing anger or indignation there was a clear sense that they were picturing themselves in the patient's or relative's place, and indeed spoke in language such as "*if I was the one in that bed*…" The doctor who exclaimed "*it was dull, dull, dull!"* for the patient in a side room was undoubtedly empathising, putting herself in their shoes (even though the patient may not have found it dull).

One participant reflected on why there might have been initial resistance to shadowing, which she suggested could have been a fear of sharing the patient's experience, or empathising too much with patients. She gave her own example of shadowing a patient with dementia, and how it evoked her own issues and fears:

> *You're afraid, when you empathise, that you'll end up with the same condition. You know there must be some human survival thing that makes them afraid of that. When my brother was dying, I actually, to begin with, I felt like I was going to have to die too. You know, you do feel like you're going to join them….That's why dementia and end of life are so powerful, because they're such frightening conditions…we're going to drown in it and you'll lose your sense of self.* [P16, clinician]

This shadower's professional background included training in psychotherapy, which perhaps influenced how she thought about her experience, with its suggestion that empathy is defended against in everyday life. The participants were in an unusual situation with patients, outside their normal role (as seen in the previous chapter) but, although a few were aware of this, and talked about 'taking off the professional hat', they did not reflect on this in depth. It may be beneficial for participants to recognise the personal challenge shadowing might present in order to prepare for it.

5.5. Subjectivity and observation

As with the example above, where a room was described by the participant as dull, clearly observations are subjective, and this subjectivity is explored further in this section.

5.5.1.'Lens'

An experienced shadower (for whom this programme was not the first experience of shadowing) observed that "*depending on what your outlook on life is will influence how you shadow*", [P18] and this appeared to be true in a number of ways; personal experience of a similar situation with their own family could have a significant influence on how patients' and families' experience was perceived or interpreted. What participants brought to shadowing determined their judgements, conscious or unconscious, about what they saw or experienced, and what their emotional response was. However, most appeared to be unaware of this, and did not temper the interpretation of their observations accordingly.

There were members of staff who talked about a personal experience of being in the position of visiting family members who were in hospital at the end of life. Some had offered to shadow because of this, and one non-clinician explicitly said she was seeking reassurance after a poor experience of seeing her grandmother die in hospital:

> *I was slightly apprehensive because I do remember being with my grandma when she died in hospital and actually it wasn't the most pleasant of experiences…So I was*

> *slightly nervous about what I was going to find but I almost wanted to see that it wasn't like that. I had that experience of seeing my grandma and I wanted to see had they…were things different?* [P5, non clinician]

She went on to say that she wanted to make sense of what she had seen when she was a relative and for this reason the shadowing experience had been positive for her, helping her to understand the care of a dying patient more from the staff's point of view:

> *They did what they needed to do and then they went on to the next patient, and they did that for them as well. So, the normal life of the ward was going on around…that's what I found a little – not upsetting- but it was an emotional, I can't really almost explain it. When something bad happens, the world doesn't end. The world around you still is going on. So that was almost an eye opener for me, to see it from a different perspective.*

This shadower constantly compared what she saw of the interaction between staff and patient, and more widely on the ward where she was shadowing, with what she remembered when her own grandparents were dying. Watching what was happening through this personal 'lens' meant that she was on the alert, and particularly sensitive to the environment and the relational care provided:

> *It was remarkably calm, but also there was some background noise, which I really liked, because I remember that whole silence thing when my grandpa was ill and as much as it was very calm, it was too silent….I just watched what was going on and while I was there …..they came over and gave him some water like on a sponge, because I had wondered about that because my grandma was on no fluid and she got very chapped lips, and so..that was quite a nice thing to see.*

This comment provides an example of how sometimes healthcare staff who take part in quality improvement projects are prone to 'comfort seeking', whereby their lens is a professional one, and there is a danger of merely checking that care is adequate rather than approaching a situation with curiosity (Dixon-Woods, Mary et al., 2014). As one participant observed, *"I reassured myself there was nothing to scare the horses"*. [P1, non clinician]

Having the same professional background did not necessarily mean having the same 'lens'. There can be different interpretations of the same issue, depending on the shadower, and their personal outlook. For example, two doctors who shadowed in the same hospital had different views on the experience for patients. One felt being on a ward was better because side rooms were too dull, and the other spoke about the peaceful atmosphere of the side room being appropriate for a patient who was dying. The shadower's personality, or personal preference and viewpoint, appeared to be the dominant influence here.

5.5.2. "*If I was in that bed*": subjective observations and empathy

There was little indication that the participants were aware that their observations were subjective. One participant was aware of the risk of making assumptions, a participant with a quality improvement outlook who was thinking, even while shadowing, how it worked as a method to make improvements. This participant commented that "*we are not that person*" [P18, non clinician]. Most others, however, did not realise that they were making assumptions, revealed by beginning comments with phrases like "*if I was in that bed…"[*P6] , and then going on to say what they would or would not like about the experience. A participant said that she tried to treat others as she would like to be treated or her family to be treated and when shadowing viewed what she saw with, at the back of her mind, "*if it was my mum*" [P11]. Others, when commenting on the type of music they could hear in the background when sitting on a ward, seemed unaware that they were making a subjective judgement about how appropriate it was for patients. This was an example of where the participants expressed empathy with the patients, but were not 'seeing through the patient's eyes', but through their own lens, shaped by their own personal preference or taste. This could also be true where their own experience or opinions or training got in the way, and their feelings of empathy might have been unreliable. It is interesting to note that none of the participants explicitly recognised that being fit and healthy might influence their judgement. For example, the clinician who described being in a side room as "*dull, dull, dull!...what* *would you do day on day, hour by hour? That is doing people's heads in"* might not have the same feelings if they were very ill or close to the end of life. The participant might therefore be projecting their own feelings onto the patient's situation. A decision to change the policy about putting dying patients on side wards (and putting them on wards instead) might therefore be based on incorrect assumptions. Assumptions and personality can get in the way of truly 'seeing through the patient's eyes', and misplaced 'empathy' by the shadower could mean that the best decisions about where to focus improvement might not be made.

Participants saw some examples of relational care which they felt demonstrated empathy on the part of the member of staff. However, one participant, reflecting on this, recognised that patients may not feel that staff are truly empathising with their situation, and gave the example of witnessing a nurse patting a patient on the shoulder. The patient had confided that they did not appreciate it, illustrating the importance of checking the assumptions made by shadowers:

> *Empathy is a bizarre concept isn't it because it is a perception isn't it..one patient might see that as quite empathic because they're thinking, oh they're physically demonstrating, there's a bit of touch there, to say I'm here with you….but actually [this patient] thought it was just a pain in the neck and thought it was quite intrusive* [P18, non clinician]

Generally, participants found it easier to describe poor relational care, which they characterised as a 'disconnect' or a lack of empathy. This might be because finding examples of empathetic care is more a matter of subjective judgement, whereas poor care is more objectively defined and amenable to a consensus about what it is.

5.6. Motivation and *"a thirst for quality improvement":* impact of shadowing on care for patients and families

Generally the emotional response felt by participants was transformed into a positive energy for changing patients' experience. Participants were normally directly or indirectly part of a project team; one team leader described how she had seen that shadowing motivated staff and engaged them with the project:

> *I think it gives them a real, a genuine insight into the lens of the patient. It gives them a thirst for quality improvements, to look at changes for improvements that they can engage in and make to improve patient experience.* [P13, clinician]

A key characteristic of the programme's method was that participants in the project teams met together after shadowing, were able to identify together where change could be made, suggest ideas for improvement and then make the changes, in some cases immediately. In other service improvement projects participants had mentioned this immediacy had been lacking, but in this project, as one participant explained:

> *Well as soon as you've been there, it makes it personal. So then all of a sudden you're wanting to do something.* [P6, clinician]

Changes to care could be seen straight away (for example, the introduction of a special menu at mealtimes for patients at end of life) and participants reflected that it was rewarding to be able to make a tangible contribution to care, and that they felt renewed motivation for work:

> *It made a connection with why you're doing it* [being a doctor] *in the first place.* [P6]

5.7. Participants' reflections on shadowing as an approach

When reflecting on their own experience, participants expressed thoughts about shadowing as a process and as a method to make improvements for patients. This included comparing it with other similar approaches, such as other types of experiential learning which they felt achieved the same aim of understanding care from the patients' perspective. Examples given included collecting narratives from patients through interviews, wearing dementia suits and special glasses, to taking therapy dogs to patients and chatting to them about their experiences[8]. Others described activities such as meal observations, where they sat among patients on a ward to notice what was happening at mealtimes in order to inform projects about nutrition:

> *…but calling it something else…. and staff, certainly at that time felt more comfortable with using perhaps other words…it made them feel more like they were working.* [P16, clinician]

This participant's observation that the language of 'shadowing' (rather than the activity itself) might have been a problem, affirms the suggestion expressed by the participants who felt their colleagues thought shadowing was not "*proper work*" and might even suggest that they agreed with this judgement. Some participants found it difficult to justify the time spent shadowing, and thought that quality improvement more broadly might not be seen as legitimate by others in the organisation. Shadowing not being seen as "*proper work"* was a strong theme which was mentioned on several occasions by different participants. There was a sense that with their colleagues under pressure because of staff shortages, it was difficult not to feel guilty or self-conscious about "*just sitting".* A barrier to shadowing was even embarrassment that they would be seen to be "*slacking off".* In spite of this, several expressed regret that they had not done more, and finding time to shadow was a genuine barrier. Generally, however, when reflecting on shadowing as an approach, participants spoke of its perceived benefits. A commissioner appeared to suggest shadowing was essential for her role:

> *It informs your decision-making. If you're working in end of life care it informs your decision making and it give you a broader perspective…I don't see how as a commissioner you can commission the services without knowing what those services are and how they are being experienced.* [P8, non clinician]

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[8] The suits and glasses are designed to simulate sensory impairment, and change tactile perception

Some referred to types of informal or unofficial shadowing. Two of the participants, both with patient experience roles in their organisations, talked about being a patient or carer themselves and watching and observing in the way they might if they were shadowing in a work situation. One described how she had used personal situations and "*ploughed it into my work".* [P16, clinician]

In terms of shadowing as a process to make improvements, participants reflected on how it impacted their working life positively. For example, a commissioner who shadowed patients in one of the care homes described how it had improved relationships with the services she commissioned, as well as bringing about change in those services:

> *It's worth taking the time to do it as well, because we all get so busy and you just think, oh, I haven't got the time to do this, but actually it had a two-pronged effect for me, so it's helped me to build the relationship with that care home and the deputy manager, and it's also informed my decision making about services.* [P8, non clinician]

Shadowing could also make an impact on personal behaviour. A junior occupational therapist who undertook several hours of shadowing (6 or 7 patients) described how even if she was not sitting and shadowing she would now "al*ways be watching things and looking out*". She gave a recent example, since the end of the programme:

> *And I had to flag some things up to the matron, you know, so they could get relayed, because some staff's attitude, I didn't like to be honest.* [P11, OT assistant]

She felt she could now recognise signs that a patient was nearing the end of life, and now did not feel afraid to inform the doctors, and even challenge their decisions. She felt that as a result of her increased confidence she had been invited, as a therapist, to be part of the hospital's end of life care steering group. This particular participant had spent more time shadowing than anyone else. However, it seems that even one experience of shadowing could make an impression, as a healthcare assistant said:

> *She was my only one that I managed to get shadowed, and that did make a big impact on me actually.* [P10, HCA]

The influence of shadowing could have an impact beyond the immediate environment and in one case reached the organisation's Board:

> *The team took the shadowing learning to the trust board – the Director of Nursing asked them to do it, and when they did….they were supposed to be doing a 10 minute presentation, but the board was so interested that the slot lasted over 30 minutes.* [P16, clinician]

This led to further funding for the project to continue beyond the life of the collaborative learning programme.

5.8.Summary

In summary, personal factors can be seen at work in the style of shadowing the participants adopted; some personalities found it difficult not to intervene in care as they accompanied patients, and others saw themselves as providing companionship, and enjoyed talking to patients. Others made themselves as invisible as possible, and made a conscious effort to '*get into the zone'* [P10] to understand what the patient was experiencing. Shadowing appears to increase knowledge and understanding of the experience of patients and families, and can evoke powerful emotions which can increase motivation to make improvements to care. However, it is not clear that shadowing increases the capacity to feel what another person is experiencing from within their frame of reference, '*to walk in somebody else's shoes'* [P18] because observations made, and interpretation of how patients feel is necessarily subjective. Subjectivity is not in itself negative, if shadowers are aware of it. Reflexivity is needed in order to avoid the possibility of making changes to care which are not appropriate. This can be built into preparation for shadowing and debriefing afterwards, to maximise the effectiveness of the shadowing process.

CHAPTER 6: DISCUSSION

6.1.Introduction

What shadowers do, and how they translate their findings into having an impact on patients' care experience has not until now been documented (Liberati, 2016). More broadly, a review of the literature has shown that the impact on staff who take part in projects to improve patient experience is an under-researched area. This study examines for the first time, through the accounts of healthcare staff, the experience of taking part in a quality improvement programme which requires participants to use the experiential technique of shadowing patients. The study has elaborated on the processes, key experiences and impacts of shadowing, and has revealed the significant place of emotion in this work. The most challenging aspects of the work of shadowing for healthcare staff proved to be emotional, rather than practical, professional, logistical or ethical. The emotions felt by shadowers in response to their experience of being with patients in this way were complex, and at the heart was the way that new perspectives afforded were 'unusual'.

Accompanying patients, seeing the familiar from unfamiliar vantage points created new emotional responses to the patients and what they were experiencing. The challenge related to both the feelings beforehand and the emotions felt by some during shadowing, and occasionally how they felt afterwards. These feelings ranged from a feeling of being slightly uncomfortable outside their usual role to a powerful personal impact for some, evoking thoughts and reflections about their own mortality, death and dying. Emotion also played an important part in bringing about engagement with the projects, through increased empathy, and personal impact for shadowers, leading to a positive feeling of empowerment and a wish to make change for patients and families. Motivation and how change came about is explored, and the relationship between emotional response, increased understanding and motivation.

As outlined in Chapter 2, a clear description of the intervention (sometimes referred to as the 'black box') is often lacking in reports of quality improvement projects (Dixon-Woods 2016) and this study, through the accounts of those who undertook shadowing, explored the process in detail. The study revealed different approaches and styles of shadowing, and moreover, how personal factors influenced judgement and interpretation of what was being observed. Findings have implications for practice, the most important being the need for recognition of the emotional challenges involved, so that appropriate support is involved. Secondly, training should be provided for teams to debrief in a reflexive way, to engender an awareness that they will bring their own lens to what they have observed while shadowing. This will help teams to avoid making assumptions about where to focus improvements.

The patients being studied were at end of life, and whilst this study did not set out to discover the experience of those being shadowed, participants reported that patients and their families generally appreciated being shadowed, as a demonstration of attention to their experience of care, and had thanked them for it. For those patients at end of life unable to respond, shadowing may be a particularly appropriate way of collecting information, similar to structured observation of care of frail older patients (Barker et al., 2016) or dementia care mapping (Barbosa et al., 2017). Shadowing encompasses the family's experience too, and it is unusual for these data to be collected in improvement projects, perhaps because it is not a policy imperative. This is a neglected area, because not only do family and other informal carers often speak on behalf of their loved ones, but their own experience is important in its own right, at what is often a difficult time.

6.2. The place of emotion

Different aspects of the place of emotion are explored here with reference to the research literature.

6.2.1. Professional detachment and defences against anxiety

This study may help to explain why initial reluctance to undertake shadowing may stem from more than practical issues, such as finding time in a busy working day. It may be due to a deeper fear of being put into an unusual, even uncomfortable situation with patients, where staff found themselves out of their usual role and found it difficult to remove the professional ‘hat’, and alter their relationship with the patients they were shadowing.

It has long been recognised that ‘the development of necessary professional detachment’ is essential for healthcare professionals (Menzies-Lyth, 1988). In a recent report, *Kindness, emotions and human relationships: the blind spot in public policy,* the historical arguments against the place of emotion in public services are explained: when the welfare state was set up it was seen as necessary for services to be professional, and fair to all: ‘some detachment and a proper sense of distance is needed to ensure that decisions are based on the experience and training of the provider’ (Unwin, 2018, p.23). This pronouncement arose from a concern that there had been a tendency by early philanthropical organisations to make judgements about who ‘deserved’ financial and other support, such as housing. It was thought that this favouring of some of those in need over others could be avoided if emotions were not allowed to influence decisions about resource allocation.

Even though professional detachment may not now be taught formally to medical and nursing undergraduates, detachment is recognised as part of the ‘hidden curriculum’ (Palmer, 2007). Detachment is a mechanism for coping with the nature of the work healthcare staff do; too much emotional involvement with patients can lead to burnout (Gillespie and Melby, 2003). In studies of trainee doctors for example it has been noted that detachment increases over time (Shapiro, 2008).

Menzies-Lyth’s influential work ‘The functioning of social systems as a defence against anxiety’ may shed further light on why participants might have found shadowing challenging (Menzies-Lyth, 1959). Menzies-Lyth’s case study of organisational life in a general hospital led to her theorizing that working in healthcare raises significant anxieties for staff and that defences are a natural reaction to the anxiety of caring for, and being in constant close proximity to patients who are sick, suffering or dying. This was suggested in the comment of one participant “*there is a fear of empathising too much”.* Menzies-Lyth (a social scientist and psychoanalyst by training) focused particularly on nursing, though it has wider application for all those working closely with seriously ill or dying patients.

> ‘Nurses are confronted with the threat and the reality of suffering and death as few lay people are. Their work involves carrying out tasks which, by ordinary standards, are distasteful, disgusting and frightening.’ (Menzies-Lyth, 1988, p.46).

The ways (techniques or strategies) that hospitals deal organisationally with fears of suffering, death and dying have been well described by Menzies-Lyth, and others in healthcare and other contexts since (Armstrong and Rustin, 2019; Campling, 2015; Ballatt et al., 2020), and particularly in nursing there has been an interest in the emotional work of healthcare (discussed below) (Kinman and Legetter, 2016). In practical terms Menzies-Lyth identified practices such as splitting the nurse-patient relationship (for example the frequent moving of nurses, division of labour, and the suppression of individuality through uniforms), depersonalisation, categorisation and denial of the significance of the individual (for example describing patients by their illness rather than name), avoidance of change, and detachment and denial of feelings. All these tactics provide forms of distancing and the means of keeping patients as the ‘Other’. Ballatt and Campling (2015), referring to Menzies-Lyth’s work, have described how ‘kindness suffers as the capacity for fellow feeling recedes’. This depersonalisation taken too far is at the heart of many of the failings in patient centred care, particularly elderly and vulnerable patients, exposed by a series of public inquiries where it was clear that ‘the person in the patient’ had been overlooked (Goodrich and Cornwell, 2008).

In this study, different styles of shadowing were adopted by participants to find a way to approach a situation which was different from their everyday work role, and sometimes uncomfortable. The participants who found it difficult not to intervene professionally, or who made judgements from a clinician’s point of view, may have found it difficult to step out of their professional role and to get alongside patients in a way that called for some loss of detachment. Indeed, to a greater or lesser extent, some participants found ways (whether intentional or not) of resisting the possibility of shadowing breaking through their professional detachment. Others shadowed in a way which did not allow them to feel close to the patients. In one case, the shadower appeared to think they were there to check whether good care was being provided, and in effect began to shadow staff rather than patients. Others were clearly ‘comfort seeking’ (Dixon-Woods et al.,2014); when shadowers did not allow themselves to respond emotionally the exercise became more shallow, an exercise in reassuring themselves that care is good, or not as bad as they feared.

Some participants avoided shadowing all together by referring to practical problems (which may have been an unconscious defence) for example that they thought it would be difficult to get permission, or that they did not have time. Looking at why the decision not to shadow was taken by some participants in the programme reveals some of these defences. While there is real pressure on staff with performance and cost cutting targets, with associated understaffing, busyness could be a useful defence to hide behind. However, as one participant pointed out, one short experience of shadowing was enough to make an impact.

Other reasons for not shadowing were expressed by team leads as a wish to work with staff on their emotions about death and dying before undertaking shadowing. Using Menzies-Lyth’s framework, this could be interpreted as worry that teams would be exposed to increased anxiety by being close to the frightening reality of death. One participant illustrated the ‘primitive fear’ that Menzies-Lyth describes by confessing to a feeling that being close to patients with dementia meant that she would ‘catch it’, and that when she spent time with her own close relative who was dying she feared she too would die imminently.

It is possible that when a consultant says that ‘my patients’ cannot be shadowed, or where a manager makes a decision that it would be ‘too much’ for their team, or criticises shadowing on the grounds that it could ‘do more harm than good,’ that these might be examples of defensive reactions to an activity which could be threatening to upset carefully conserved equilibrium and detachment, and the suggestion of change.

Crucially, those who did allow themselves to lower their defences, and lose the protection of their professional detachment or ‘hat’, found the experience rewarding.

This chimes with Menzies-Lyth's view that the very techniques used to reduce anxiety may in fact be making the problem worse for healthcare staff. Detachment or disconnect from patients can lead to 'deprivation of personal satisfaction' (Menzies-Lyth, 1959). Indeed in a review of stress in hospice staff it was found that the emotional challenge of caring for dying patients and their families was mitigated by the rewarding relationships that develop when staff are able to care for them over a period of time (Goodrich and Harrison, 2015).

It has been noted that with increased detachment comes decreased empathy (Haque and Waytz, 2012). Therefore detachment can have implications for the quality of patients' experience, and suggests that the challenge is for healthcare staff to find the right amount of detachment to benefit both themselves and their patients. There is a complex relationship between burnout and empathy in health professionals (Wilkinson et al., 2017). It is possible that if those who care for them do not 'regulate' their distance from patients emotionally, too much empathy can lead to burnout, but then a symptom of burnout is depersonalisation, a lack of empathy (Firth-Cozens and Cornwell, 2009).

There was a suggestion from some participants that too much professional detachment or strategies developed to cope with the physical and emotional challenges of looking after patients had led to their forgetting the rewarding side of caring for patients. If they allowed themselves to 'go the extra mile' for patients, or lower their defences, they rediscovered feelings of job satisfaction, and of why they wanted to work in healthcare, and spoke of how the experience of shadowing touched them emotionally in a positive and even helpful way.

6.2.2. Emotion in healthcare, empathy and emotional response

There are different ways of understanding the part emotion plays in healthcare work and different ways of managing emotion (Kelly and Smith, 2016; Heyhoe et al., 2016). The concept of emotional containment has been described as the ways in which emotion is experienced or avoided, managed or denied, kept in or passed on, so that its effects are either mitigated or amplified (Menzies-Lyth, 1988). It is seen as a positive concept if emotion is managed successfully. The concept of emotional labour in healthcare: 'the induction or suppression of feeling in order to sustain an outward appearance that produces in others a sense of being cared for in a convivial, safe place' (Hochschild, 1983) is an important one because it recognises the emotional effort involved for healthcare staff in their work (Brighton et al., 2019). Findings from this study do not support a suggestion by Boulton and Boaz (2019) that shadowing increases emotional labour; this concept, which involves the suppression of one's own emotions for the sake of the patient, does not appear to be accurate in relation to shadowing. However, the suggestion in the same evaluation (Boulton and Boaz, 2019), that shadowing could increase 'emotional burden', a different concept, should be taken seriously. If shadowing increases anxiety or distress it is possible that it could make working life more difficult (and therefore perhaps could make emotional labour more difficult). The implication for practice (see section 6.4.2) is that when shadowing is undertaken there should be corresponding training and support in place to help participants manage emotion. The key message is to recognise the place of emotion in healthcare, and that shadowing may involve emotion in a new way, which is not the same as emotional labour, and need not be an increase in emotional burden, if it is undertaken as part of a wider team effort incorporating debriefing on the experience, and it is understood that changes can be made for patients as a result.

Empathy is the capacity to understand or feel what another person is experiencing from within their frame of reference, that is, the capacity to place oneself in another's position. Baron-Cohen, who has studied empathy extensively, separates these two aspects of empathy (understanding and feeling). Cognitive empathy is how we understand other people and affective empathy is a sense of sharing those feelings, or an emotional connection (Baron-Cohen, 2012). It has been claimed that shadowing can increase empathy, by allowing healthcare staff to engage emotionally with patients' and families' experiences (Shaw et al., 2014, DiGioia 2011). However, none mentioned their own empathy explicitly or claimed shadowing had increased their empathy, although they may have engaged emotionally with the shadowing experience, and the patients they were with.

There are possible explanations for why participants did not refer to an impact on their own empathy. Some participants may not have understood or been clear what is meant by empathy, as it is not an 'every day word' (Goodrich 2009), and may be too generic a term; those participants who were interviewed, and asked about empathy, or empathetic care appeared to struggle slightly with the terms. If pressed, they reflected on kind or 'lovely' relational care role modelled by colleagues. In one case a nurse recalled how she had learned how to show respect and consideration to patients when she was a student nurse by watching experienced nurses' behaviour. It seemed easier to describe poor care which was unkind or thoughtless, or cursory.

In the empathy scale included in the questionnaire administered to participants before and after shadowing, empathy was described in practical terms, with statements inviting agreement or disagreement, such as 'I can predict how my patient can feel'. Hence another explanation for reluctance to claim empathy may be that participants realised, having shadowed, that the patients' experience was not what they had thought it was, and therefore did not want to claim that they were empathetic. The clearest example of this was the surprise expressed by busy clinical participants, about how 'nothing happened' for patients for significant lengths of time, and how time lay heavily for them. The participants had assumed the ward felt busy for everyone.

6.2.3. 'Through the eyes of the patient' – is this possible or even desirable?

An emotional response, which appears to galvanise healthcare staff into action, in itself positive, should, however, be treated with caution. The context for the patient, and the patient's preferences may not be the same as the shadower's. In other words, shadowers need to be aware that they bring their own individual perceptions and judgements which might, if not reflected upon, result in jeopardising the intended goal of making improvements which will make a difference to the experience of care for patients. Assumptions were sometimes made about how the patient or family was feeling, or would feel about their care, the environment and interactions with staff. In an attempt to put themselves into the patient's shoes, participants' responses were more an indication of how they would feel if they were in the patient's place. The most striking example was the decision made by one improvement team to change the policy on putting dying patients in side rooms, because, in their perception it was "*dull, dull, dull*" and '"*if I was dying I would want to know that life was still going on around me".*

This is a particular example of how the best intentioned wish, often expressed by people working in healthcare, to treat others as you would like to be treated, or you would wish your own family to be treated (Wood, 2008) might be unhelpful. In some cases, shadowers checked their impressions with the patients, but in many cases the patients were not able to have a conversation.

Although seeing through the patient's eyes has been a mantra in patient experience work for decades, this study demonstrates that it is not possible because, as one of the participants said, "*you are not that person*". It is not possible to know completely for example, the patient's context, their life experiences up until this point, or for the (usually) younger and healthier person who is shadowing, how it feels to be ill or dying. It is nevertheless valuable to attempt to understand patients' and relatives' experience (and most quality improvement programmes do not do this). Moreover, many observations were material and objective examples, where making change would be an improvement for patients and families (such as the poor physical environment or lack of offered refreshment for relatives, or the inappropriate food for patients), because "*poor care is always poor care*" (P11).

The importance of reflexivity for researchers when shadowing has been highlighted, (Liberati et al., 2015) and this study points to how it would be equally valuable for non-researchers who undertake shadowing, to reflect before, during and after shadowing how they are bringing aspects of themselves to what they observe. Reflexivity, 'critical assessment of presuppositions' is not consistently taught as part of clinical training (Landy et al.,2016). The concept of reflexivity in relation to shadowing, being made aware of how they are constructing the social situation they are in, and being conscious of knowledge production as it is being produced should be adapted to be a practical action built into training, preparation and debriefing for participants.

6.3. Quality improvement and motivation: how did change come about for patients?

In a systematic review of the use of patient experience data for quality improvement in healthcare settings, it was shown that approaches introduced to the NHS in recent years have not been 'acceptable' to staff (Gleeson et al., 2016). For example, staff do not find the time, or enjoy these projects. In another review it was shown that quality improvement projects which focus only on improving process have a negative association with worker satisfaction (Dixon-Woods, 2016).

Among participants in this study, motivation to make change, and engagement with the project appeared to be affected positively by the experience of shadowing. Some gained new understanding through watching staff provide care, even where the patient was not very responsive, in a way which one participant described as similar to learning through the role modelling of senior nurses when she had been a student nurse decades ago. Other participants, through taking time to ‘get into the zone’ with patients, began to share their experience and understand better what it was like, and what was important to patients and families.

A review of formal evaluations of programmes to improve quality in healthcare, identified factors needed for success: ‘the first of which was convincing clinical teams that there is a real problem to be addressed. Those designing and planning interventions should be careful to target problems that are likely to be accepted as real’ (Dixon-Woods et al.,2012), and the authors suggest using patient stories to secure emotional engagement and engage the clinicians in defining what they would like to improve. This study has demonstrated that shadowing equally appears to achieve both these things.

The experience of shadowing, and being with patients at end of life seems to have an emotional impact for some staff, which increases their motivation to engage with the improvement programme and to make the experience of patients and their families better. The concept of intrinsic motivation may illuminate the link between empathy and motivation to engage in improvement efforts. (Herzer and Pronovost (2014) have asserted that quality improvement initiatives, if they are to engage doctors/clinicians must ‘light the intrinsic fire’. Shadowing appears to reignite the desire to provide kind and compassionate care for patients, and to make changes to achieve this. Participants spoke of being reminded through shadowing why they had wanted to work in healthcare.

Participants in the study found it rewarding to be able to see through shadowing how the experience of patients could be improved, and then to make the changes themselves. Often data are provided about patient experience by researchers or others, and staff are asked to make improvements, but the emotional engagement is lacking; shadowing closed this gap. For example, a participant (a junior therapist) spoke of observing the way that relatives were treated when they came in to visit, and made sure that this was changed immediately, so that they are now routinely offered refreshments. An examination of the final project reports written by teams shows that within the 9 month time frame of the Living Well programme changes were made to care. These included a change in the way food was offered to end of life patients (with a new more appropriate menu provided by the catering team), a quiet room for relatives, a new, patient-centred, symptom chart, a 'tell us about you' form for patients and families to complete, communication skills workshops for staff, and earlier identification of people with learning disabilities who need end of life care (see appendix H).

6.4. Implications and recommendations for policy and practice

The way a patient is treated as a person is the third component of healthcare quality, alongside safety and clinical effectiveness. There has been some focus on improving patients' experience, but the policy climate has been more orientated towards measuring patient experience rather than understanding it. The premise behind the quality improvement programme which is the focus of this study is that there is a need to understand how patients experience the service, in order to improve it. The second premise is that experiential approaches like shadowing are necessary to understand the experience 'through the patient's eyes'. However, the literature review revealed that very few experiential methods in quality improvement projects are documented in research studies, and even fewer describe outcomes (for patients). Outcomes for staff have not been studied; at best, the impact on staff who take part is referred to incidentally. The impact on staff who take part in healthcare quality improvement initiatives is clearly an under researched area. Researchers in one study observed that the measures chosen in evaluations of projects to improve patient experience may overlook a key outcome: 'deeper, longer term changes in attitudes and behaviours' in staff (Robert et al., 2015, p.2). A nurse specialist is quoted, saying, "I saw staff reconnect with their fundamental core beliefs and values, which has to impact not only on their wellbeing but on that of the next patient and relative they meet. Sometimes you cannot count what really counts." (Robert et al., 2015, p.3).

There is thus a gap in quality improvement research which links experiential methods to understanding and collecting data on patient experience (with varying degrees of involvement of patients and families), and making improvements for patients. There has been a focus in research on determining what makes healthcare staff motivated to make quality improvements and a call to appeal to their intrinsic motivation(Dixon-Woods, 2016; Dixon-Woods et al.,2012), but more attention needs to be paid to 'acceptability' of approaches introduced to NHS staff. This study contributes to this practical concept by highlighting the practical and emotional challenges for staff.

A review of shadowing (Liberati, 2016) as a potential research method concluded that more information was needed on how researchers convert findings into impact on patients' care experience. This study shows that non-researchers, with careful training and preparation, can collect information through shadowing. Thus it makes an effective impact on patients' care experience if the same people both shadow and then make the changes for their patients. This eliminates the interim step of a researcher collecting data and feeding it back to staff. This study shows how change comes about in terms of increased understanding and emotional response. It has also provided detail on the 'black box' of the intervention which is so often lacking in reports of quality improvement projects. Liberati concluded that 'a thorough examination of shadowing's practical, methodological and ethical challenges is still lacking': this study has contributed insights into each of these. The review called for 'fuller, more nuanced and more reflexive research accounts of the experience of shadowing from multiple perspectives – the observers, patients and caregivers' and this study has provided this for the observer-caregivers.

6.4.1. Policy and quality improvement

For front line teams in the NHS, collecting patient experience data can feel unnecessarily onerous and punitive particularly if staff are unclear about the purpose of collecting data

(Robert, Cornwell and Black, 2018). However, findings from this study show that collecting data through shadowing appears to be more acceptable and indeed staff demonstrated enthusiasm for this way of discovering more about their patients' experience. Study participants recognised that data were being collected with the purpose of improving the experience of their patients. Currently policy directives and initiatives generally do not make the link between patient experience data collection and quality improvement. Shadowing is a way of collecting data that adds another dimension, by appearing to engage and motivate staff to make improvements, appealing to intrinsic motivation, rather than external motivating factors, such as financial incentives.

Quality improvement methods encourage staff to collect data as far as possible in 'real time', as locally as possible, so that they can act upon it immediately. The data collected through shadowing meets these criteria; teams have de-briefed following shadowing, shared what they have observed, and implemented ideas for improvement, in some cases immediately. Thus realisable outcomes for patients are seen to be directly linked to the activity of shadowing.

Shadowing encourages an understanding of what is important to patients by enabling staff to see care from their perspective, and raises a key question for policy makers, about whether the right data are being collected, and whether the NHS is measuring and acting on what is important to patients.

Shadowing is particularly appropriate for patients at the end of life when they either cannot respond to questions, or staff are reluctant to bother them with questions. The experience of the family becomes particularly relevant, both because they are speaking on behalf of their loved ones, and because their own experience is important in its own right, at what is often a difficult time. The inpatient surveys include a question about whether family and friends were involved in care, but does not ask about what the experience was like for them. Shadowing encompasses the family's experience, and as it is unusual for these data to be collected, provides a valuable insight.

Government policy related to end of life care includes the first national End of Life strategy published in 2008 (Department of Health and Social Care, 2008) and in 2015 a new framework was published building on this, which sets out six ambitions, all framed from the person who is at the end of life's perspective (National Palliative and End of Life Care Partnership, 2015). The framework states that 'the need for support from empathetic and competent health and care staff is as important for carers, families and those who are bereaved, as it is for the dying.' The strategy also states that 'all those who are part of the local health and social care system that cares for the dying and bereaved should seek to sensitively collect and use a wide range of information so that they can assess progress towards our ambitions. Palliative and end of life care organisations need to…invest in collecting and using data.' Collecting information through shadowing is an appropriate and relevant approach to data collection in end of life care, and policy makers could specifically recommend it.

This study makes a case for introducing shadowing to the range of tools available both for collecting data and improving patient experience. Shadowing could add value by motivating and engaging NHS staff, another government priority (NHS Employers, 2013). Although much is said rhetorically about collecting patient experience data for improvement, this is not usually accompanied by practical advice and examples, so that staff may struggle to see the connection.

6.4.2. Practice – implications and recommendations

These findings point to a need to redesign the training curriculum provided for shadowing. When preparing teams for shadowing, in addition to the current practical guidance, which emphasises that it is a purposeful and structured activity, there should be preparation for the emotional aspects of shadowing. There should be an acknowledgment that shadowing places staff in a situation with their patients which is different from usual, and that it might be uncomfortable to step out of role in this way, and tempting to intervene in care. Discussion should cover this challenge to professional detachment. It should also be made clear that shadowing is a legitimate activity, for which participants have permission, even though they may feel uneasy that it is not ‘proper work’. Colleagues can be prepared for the presence of shadowers by explaining its purpose, and by sharing the written guidance for shadowers.

Training will include guidance on the importance of providing emotional as well as practical support for those who might find shadowing difficult, or personally challenging, both before and after shadowing. Leaders need to help their teams to do the shadowing work, and advise on how to contain their emotions.

There should be guidance on being aware of how personal factors will influence judgement (reflexivity). Ways of mitigating this would be to encourage shadowing in pairs, logging what is seen in a standard way, and reframing shadowing as a group activity. Emphasis can be placed on the importance of debriefing, and sharing and discussing the implications of what they have learned for changes for patients. Members of the project team will all bring valuable observations that could be interpreted in different ways.

When teams come together to discuss their experience of shadowing, through listening to each other, they can gain a shared understanding. So for example if one team member had only responded with cognitive empathy (observing faults in processes, or broken equipment for example) and another with affective empathy (noticing how patients did not receive comforting touch or words for example) this could be combined to create a deeper understanding of patients’ experience, and how to improve it. It appears that, in terms of wanting to make changes to the patient’s experience it did not matter whether it was cognitive or affective empathy. Shadowing should be a team activity for this reason. Team debriefs are also an important source of support in case the experience of shadowing has been difficult.

The potential ethical risks of shadowing need to be acknowledged, and can be mitigated by preparing teams thoroughly, and supporting them throughout. For example, it should be made clear that the risk of vulnerable patients being exploited should always be avoided, for instance by approaching them and their relatives sensitively to ask permission, and explaining that they can decline to be shadowed. It should be emphasised that shadowers should step away if there are situations where it is inappropriate for a stranger to be present. Many of the anxieties that individuals showed before they began shadowing can be addressed through having a secure ethical framework. For example, the fear expressed by some of seeing poor care can be addressed by discussing this as a team beforehand, and agreeing a process to alert the appropriate member of staff should this happen. The apprehension about being intrusive, and concerns for patients and families can be dispelled if ethical issues are set out clearly beforehand."

A summary of findings was presented to the chief executive and head of quality improvement at the Point of Care Foundation and they were invited to discuss the implications for shadowing in practice. This discussion resulted in a number of key points (table 5):

Table 5: Discussion of findings with colleagues: their key points

- These findings point to a need to redesign the training curriculum provided for shadowing, and make it more thorough.
- There needs to be an emphasis on making shadowers aware that they bring their own lens to the experience, and therefore to support them to be reflexive.
- Ways of mitigating this would be to encourage shadowing in pairs, logging what is seen in a standard way, and reframing shadowing as a group activity.
- Emphasis will be placed on the importance of debriefing, and sharing and discussing the implications of what they have learned for changes for patients. Members of the project team will all bring valuable observations which could be interpreted in different ways. The ladder of inference or something similar could be used as a framework for discussion (Senge, 2010). Participants need to be encouraged to undertake shadowing with curiosity and humility.
- The different anxieties felt by participants before they started shadowing need to be acknowledged, and advice given. Training will include guidance on the importance of providing emotional as well as practical support for those who might find shadowing difficult, both before and after shadowing. Leaders need to help their teams to do the shadowing work, and advise on how to manage their emotions.
- It was felt that this study has shown that shadowing as an approach is a low cost, low tech way of collecting information about patients' experience. It can be described as a tool for understanding patients' experience from their perspective, (rather than 'increasing empathy', and rather than 'seeing through their eyes', or putting oneself in their place).
- Bridging the gap between 'work as imagined and work as done' is a key concept in patient safety, and shadowing could contribute to this; it was striking how some participants expressed surprise at what they observed.
- It may be better to think of shadowing as a skill, rather than a quality improvement 'method'. It needs to be taught to an appropriate standard, but then can be used flexibly.

Practical guidance for shadowers has been produced, drawing on the study and already shared with clinical teams currently involved in improvement projects (2019). An online training module has been recorded (May 2020). See appendix J for details of all dissemination activities.

The shadowing exercise should be situated at all times within the context of its purpose to improve care for patients and their families, so that it does not become exploitative. It is strongly recommended that, to ensure this, a 'gold standard' for shadowing is developed (in addition to existing guidance), which draws on the evidence produced in this study. This would establish the rigour of shadowing as a rigorous approach and provide reassurance for those who undertake it.

6.5. Critical reflections of the thesis

The NHS context of the study raised some practical issues. The challenge of conducting interviews with very busy staff in the NHS became apparent, and the pragmatic need for flexibility of interview method. Face to face or Skype interviews were offered, with the option of a telephone interview if this was not possible. 12 telephone, 7 face to face and one Skype interview took place. The technical issues with Skype had not been anticipated: when offered a Skype call most staff had to decline, either because they had no access to a Skype account at work, or where Skype or facetime was tried the wifi signal was not strong enough on hospital premises.

The quantitative element to the study proved to be challenging, in terms of responses achieved, because of an unexpected factor related to the reality of working life for the teams: few of the same participants were able to attend both the first and last learning events where the survey was administered.

The position of researcher might have influenced some of the responses, because I was part of the organisation which ran the programme in which the participants were enrolled. It is possible that the participants held back from making critical comments for example. Being an ‘insider’ can also be a strength, (Kerstetter, 2012; Dwyer and Buckle, 2009), for instance, it was helpful to establish a rapport with the interviewees, because they knew that I understood the programme. An issue for a professional doctorate is the necessity of being objective when analysing the data and interpreting the findings. The researcher’s experience of helping to support teams on previous programmes was useful; knowledge gained contributed to questionnaire design and aided interpretation of data. A pitfall could have been when analysing and interpreting data, to separate the researcher’s understanding from participants’ understanding of the experience. This was addressed by being mindful of my position, and putting it aside, to listen carefully to the participants’ accounts when interviewing them, and use follow-up questions as much as possible to explore the participant’s meaning and interpretation of their experience.

Further research could deepen some lines of enquiry, for example to build on this study using a different approach, conducting a small number of in-depth interviews, focusing on fewer questions and use IPA to analyse the findings. It would be interesting for example to understand better the difference between clinical and non-clinical participants’ experiences and reactions, and whether professional training might be inhibiting to the shadowing process. Some participants were uncomfortable with describing themselves as having empathy with their patients or even using the word ‘empathy’, and this could be explored further to understand why this might be. Lastly, participants seemed to be unaware how subjective their comments were about what they had observed and it is possible that if they were encouraged to discuss this further in depth they might reveal more awareness. In terms of the participants’ accounts it is important to bear in mind that their subjectivity might render them occasionally unreliable, and further research using an ethnographic approach could be valuable to compare the researcher’s observations with the shadowers’ observations.

However, the strength of the study was that it explored the experience and reflections on the shadowing process, itself a reflective approach to quality improvement, and this, as far as is known, has not been done before.

6.6. Conclusion

Initial anxieties and fears about shadowing appeared to be generally unfounded, and many spoke of it being a rewarding experience, and that it ‘reconnected’ them with patients and their own motivation to care. For some it had a powerful personal impact emotionally, intensified for some by shadowing patients who were dying. Participants reported increased understanding of the experience of care and went on to describe improvements they had made to the care experience for patients and families. Shadowing enables cognitive and affective empathy with patients, which combined, works to motivate staff who with the right preparation and support can develop the skill to make real changes to patients’ and families’ experience of care.

The challenge to taking up shadowing is not primarily logistical (time consuming) or financial (resource intensive) but is emotional and calls for support for staff to be aware that it will place them in an ‘unusual’ situation with their patients which may initially feel uncomfortable and may involve conscious managing of emotion.

Although much is said rhetorically about collecting patient experience data for improvement, this is not usually accompanied by practical advice and examples, so that staff may struggle to see the connection. This study makes a case for introducing shadowing to the range of tools available both for collecting data and improving patient experience. Most methods for assessing quality in healthcare are objective in nature: participants in the Living Well programme were, for example, recording length of stay, measuring time taken for transfer from emergency admission to treatment, and auditing the availability of anticipatory medication. Shadowing has been shown to be a subjective approach which can be used alongside to balance, complement and add crucial insight to the assessment of the quality of the care experience.

The Covid-19 epidemic 2020 means that the current context (as at summer 2020) in the healthcare service precludes shadowing for the foreseeable future, but nevertheless it has focused attention on death and dying in hospital and care home settings, and the new understanding demonstrated by the teams in this study is timely for all those caring for patients at end of life.

APPENDICES

Appendix A: Scoping review: summary table of papers included in the initial review

	Reference	Study type	Summary of purpose	Reason for inclusion	Comments
1	Mockford C et al. (2012) The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal for Quality in Health Care* 24(1),28-38.	Systematic review	To identify the impact of PPI on NHS services and to identify the economic costs	Includes a small section on impact on attitudes of service users and providers	States that many studies noted that working with service users contributed to changing health professionals' attitudes, values and beliefs about the value of user involvement
2	Brett J et al. (2014) A systematic review of the impact of patient and public involvement on service users, researchers and communities. *Patient* 7,387-395	Systematic review	To identify impact of PPI on service researchers and communities	Looks at process of collaborative working between service users and professionals	Focus is service users and communities, not healthcare staff
3	Gleeson H et al. (2016) Systematic review of approaches to using patient experience data for quality improvement in healthcare settings. *BMJ Open* 6(8)	Systematic review	To explore how patient-reported experience measures are collected, communicated and used to inform healthcare QI	Includes Experience Based Codesign	Comments that relatively new field concludes that in context of QI more attention needed on measuring impact on patient experience

4	Ocloo J and Matthews R (2016) From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Quality and Safety* 0,1-7	Narrative review	Not stated but appears to be to make the case for better PPI	Includes six principles for coproduction	Presents argument for empowerment-not objective.
5	Clarke D et al (2017) What outcomes are associated with developing and implementing co-produced interventions in acute healthcare settings? A rapid evidence synthesis *BMJ Open (in press)*	Rapid evidence synthesis: meta analysis of qualitative studies	To identify and appraise reported outcomes of coproduction as an intervention to improve quality of services	Examines high quality primary studies. Looks at outcomes including staff	Most relevant review paper
6	Tsianiakas V et al.(2011) Enhancing the experience of carers in the chemotherapy outpatient setting: and exploratory randomised control trial to test impact, acceptability and feasibility of a complex intervention co-designed by carers and staff *Supportive Cancer Care* 23,3069-3080	Exploratory RCT	To test feasibility and acceptability for patients and carers	Describes outcomes/benefits clearly	Doesn’t discuss impact on staff
7	Liberati EG (2016) What is the potential of patient shadowing as a patient-	Editorial review	To present the evidence for shadowing as a method	Draws together papers on shadowing. Includes ten practice	Focus is shadowing as research not QI method

	centred method?*BMJ Quaity and Safety* 0;1-4			principles for shadowing patients	
8	Dixon-Woods M and Martin G (2016) Does quality improvement improve quality? *Future Hospital Journal* 3(3),191-4	Commentary /evidence review	To consider QI challenges and why evidence of effectiveness is mixed. To suggest ways to improve.	Summarises current issues in QI	
9	Van der Meide H (2013) Giving voice to vulnerable people: the value of shadowing for phenomenological healthcare research *Med Health Care and Philos* 16, 731-737	Ethnographic case study	To show what shadowing can achieve as a research method	Describes shadowing in detail and reflections on being shadower	Research not QI project
10	Donetto S et al (2015) Experience-based Co-design and Healthcare Improvement: Realizing participatory design in the public sector *The Design Journal* 18(2), 227-248	Discussion paper with illustrative case studies	To reflect on EBCD as a method in healthcare	Includes emotional impact on staff	Discusses co design and power relations
11	Shaw J (2014) Shadowing: a central component of patient and family-centred care *Nursing Management* 21(3), 20-23	Practice case study	To describe PFCC method and how shadowing works	Includes emotional impact on staff	Based on reflective logs kept by participants

12	Adams M, Robert G, Maben J (2015) Exploring the legacies of filmed patient narratives: the interpretation and appropriation of patient films by health care staff *Qualitative Health Research* 25(9), 1241-50	Ethnographic evaluation	To examine the impact and meaning of filmed patient narratives	Looks at impact on staff as well as patients.	High quality study. Useful summary of relevant theory.
13	DiGioia A(2011) Patient and family shadowing: creating urgency for change *JONA* 2011;41(1):23-28	Descriptive, practice paper	To describe shadowing as a QI method	Detailed account of how shadowing was and should be done	Only detailed account of how shadowing should be done as QI method. Claims positive impacts of shadowing
14	DiGioia A (2007) Patient and family-centered collaborative care: an orthopaedic model *Clinical orthopaedics and related research* 463,13-19	Primary evaluation/case study	To demonstrate effectiveness of PFCC method	Method and outcome described clearly	Outcomes for patients only
15	Vennik D et al (2016) Co-production in healthcare: rhetoric and practice *Int Rev Administrative Sciences* 82(1),150-168	Primary evaluation study	To evaluate four EBCD projects	Good quality study. Service improvements clearly described	Service improvements for patients (not staff)
16	Boyd H (2011) Improving healthcare through the use of co-design. *The New Zealand Medical Journal* 125:76-87	Primary study	To describe method and project outcomes	Outcomes clear	Outcomes for patients (not staff)

17	Robert G et al (2015) *BMJ* 10 Feb 2015;350:g7714	Case study	To describe method and give examples of outcomes	Includes impact on staff	Outcomes clear
19	Locock L et al (2014) Using a national archive of patient experience narratives to promote local patient-centred quality improvement: an ethnographic process evaluation of 'accelerated' experience-based co-design *Journal of Health Services Research* 2014 19(4), 200-207	Ethnographic process evaluation	To evaluate a modified version of EBCD method	Good quality paper Discusses benefits for staff	Includes emotional impact on staff
20	Donetto S Tsianakis V and Robert G March 2014 *Using Experience-based Co-design to improve the quality of healthcare: mapping where we are now and establishing future directions*	Report of survey findings	To gather information on practitioners' experiences of using EBCD	Includes staff reflections on emotionally demanding impact for them of method	Includes survey results on observation, filming and alludes to negative impacts
21	Bowen S et al. (2013) How was it for you? Experiences of participatory design in the UK health service *CoDesign: International Journal of Cocreation in*	Project evaluation	To describe and discuss project and method used	Experiences of using method	Critique of method by participants rather than impact on them

	Design and the Arts 9(4), 230-246				
22	Tsianakas V (2012) Implementing patient-centred care: using experience-based co-design to improve patient experience in breast and lung cancer services *Supportive Care in Cancer Care* 23(10), 3069-80	Partipatory action research project	To show how EBCD method identified and made improvements	Meets CASP criteria. Outcomes clearly described.	Outcomes for patients (not staff)
23	Farr M (2010) *Patient centred care and Experience Based Codesign; The King's Fund evaluation report* London: The King's Fund	Realist evaluation report	To evaluate the success of a large EBCD project	Includes interviews with staff and patients about the method	Looks at power relations

Papers 1, 5, 9,10,11, 12,14,17,19, 20 include impact or outcomes for staff.

APPENDIX B: PFCC Programme background information

Living well to the very end - Patient and family-centred care (PFCC) programme
Information for applicants

Contents

1. 'Living well to the very end' patient and family centred care programme:

'Living well to the very end' is a patient and family centred care programme, developed as a partnership between the Point of Care Foundation and NHS England. It is supported by the Health Foundation.
This programme focuses on the care of people at the end of life, within generalist, rather than palliative settings. Using an evidence-based and radical approach, 'Living well to the very end' uses a collaborative methodology based on the IHI's Breakthrough Series collaborative. It is truly unique in the extent to which it draws on patient shadowing to help teams understand the experience of patients and

families, and to create the urgency for change. This programme builds on the successful programme run by The King's Fund and The Health Foundation from 2010 to 2013.

Following the success of the 2016 'Living well to the very end' cohort, we are looking for 20 multi-disciplinary clinical teams from health and care provider organisations across the UK, to participate in the next phase of the programme. We welcome applications from NHS providers of acute, community and primary care, as well as non-NHS providers of health and social care. We are looking for teams which have already demonstrated commitment to transforming patients' experience of care, and invite them to work with us to transform end of life care. This work will complement existing improvement work, appeal to the values of staff, and help sustain and spread the improvements already made. Participating teams will also receive mentorship from those who have led this work in participating teams in previous cohorts.

There has never been a greater focus on patients' experience as a key component of quality, nor greater acknowledgement of the value to staff of delivering excellent care. But the NHS still has some way to go before it achieves the vision of reliably providing excellent patient experience. Through this programme we are working to support organisations and frontline staff to achieve demonstrable improvements in care for patients and in the experience of staff delivering care across the UK.

The quality of care at the end of life care has come under particular scrutiny, with significant variation in patients' and families' experience. With the publication of Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015-2020, there is now a framework to do just this for care at the end of life. This programme will target the practical challenges that are a priority for you. It will provide you with the opportunity to take the lead in this area, and to be an exemplar.

2. Programme aims:

The programme supports participating organisations and teams within them to:

- develop capacity to deliver high-quality patients' (and families') experience of care
- develop capacity to improve the experience of staff
- promote patients' experience as a high priority on the quality agenda alongside safety and clinical effectiveness
- build on the synergies that exist between work in patients' safety and patients' experience, to enhance the effectiveness of both areas of work
- spread learning and build capacity across their organisation.

3. Who is the programme for?

The programme is for multi-disciplinary teams who work in end of life care in generalist, rather than palliative care settings. Whilst the work can be supported and/or guided by palliative care specialists within the multi-disciplinary team, it must take place in a generalist setting. It is also critical to success that teams are supported in this work by leaders within their organisations, and so we ask that the application form demonstrates explicit support from an executive sponsor and a clinical champion, the definitions of which are set out in the team roles section below.

We are seeking applications which demonstrate:

- A real commitment to learning
- clearly stated aims and objectives of the proposed improvement work and consideration of how the anticipated outcomes could be measured
- commitment to considering care from patients' perspectives, and involving service users and families in your improvement work
- consideration of what you want to get out of the programme and what you hope to achieve for your service
- meaningful executive and senior clinical sponsorship for the work
- commitment to improving staff experience as well as patients' experience

4. Benefits of the programme/key features:

The programme is jointly led by clinicians and quality improvement experts from NHS England (South), the National Clinical Director for End of Life Care and the Point of Care Foundation. Those on the programme will also receive coaching and mentorship from those who have led projects in participating teams of previous cohorts. Together our faculty will deliver learning events and rapid improvement days followed by two 100 day action periods, during which you will be supported by expert coaching and mentoring to undertake rapid improvements. We will also work with you to disseminate your work.

The programme is designed based on the well-tested methods for improvement:

- the Institute for Healthcare Improvement's work to identify the key drivers of patients' experience
- the Model for Improvement
- the Patient and Family-centred Care methodology devised by the University of Pittsburgh medical centre

The programme offers:

- two days of learning events where we bring teams together, followed by 100 day action periods during which you will be supported to undertake rapid improvements
- practical support for your teams from our faculty experts

- mentorship and coaching from those who have led projects as part of previous participating teams
- assignments and learning materials
- webinars to aid communication and sharing between events
- the opportunity to showcase your work
- support with disseminating your work

The curriculum includes:

- Patient and Family-centred Care methodology and practice
- techniques to understand your patients' experience
- devising high-quality measures for improvement
- using data for improvement
- understanding and improving staff experience
- engaging frontline staff in improvement
- building staff resilience
- evaluating your work and demonstrating impact

5. Team roles and commitment:

Each team should be comprised of a Guiding council, and a Working or Core group. The Guiding Council should be made up of your Executive Sponsor, who provides organisational leadership for the work, your Clinical Champion who provides clinical leadership, your Key Contact who acts as the bridge between your team and the Point of Care Foundation Faculty, a Scribe who can coordinate meetings and ideally a patient or carer. Further description of these roles are set out in the FAQs below and we ask that individuals are identified for these roles as part of your application.

The Core or Working Group provides the functional management of the project and will be supported by the Guiding Council. The team members of this group will depend on the care experience you are working on, but will typically comprise of 6 individuals, including a senior nurse, doctor and manager. The core team must have the time, resource and support from within their organisation to carry out this work effectively, and we advise that the Working group meets weekly for half an hour.

We are asking participant organisations to commit to the programme for ten months from April/May 2017. We also ask you to secure active sponsorship from the Board through an identified Executive Sponsor and Clinical Champion, as well as identify a Key Contact to act as a bridge between your team and the Point of Care Foundation. Three members of your team will be expected to attend the learning events, and as learning is cumulative we ask that where possible the same three team members attend both events. Members of your team will also be expected to attend the learning webinars between the events, and to complete set assignments throughout the programme, which are designed to help facilitate your project.

6. Patient and family involvement:

Patients' and families experiences are at the centre of this work. We will be asking in your application how you intend to incorporate involvement into your work, building on the approaches to patient and public involvement that are already used in your organisation. As part of the programme will also provide training to help your team really see the care experience through the patient's eyes, and practical tools to involve patients and families in your work, and your team will be expected to use these throughout the programme.

7. Cost:

There is no cost to participating in this programme. Your organisation's contribution includes enabling staff time to participate in the programme and carry out the improvement work.
You will also cover costs of travel (and accommodation if needed) to two learning events plus a potential peer-review visit to another organisation.

8. Key dates:

Please note the follow dates below for the application timeline.

Date	**Activity**
24th February 2017	Applications open
31st March 2017	Applications close

Please note the below dates of activity that your team will be expected to attend if accepted on to the programme. **All applicants will be notified of the outcome of their application before 28th April 2017**.

Date	**Activity**	**Location**
April – May 2017	The Point of Care Foundation Faculty will be in touch to organise an introductory site visit to meet your team in April or May.	Local
7th June 2017	Learning webinar – introduction to the programme	
13th July 2017	Learning event 1	London

14th July – 18th October 2017	***100 day action period for rapid improvement***	***Local***

6th September 2017	Learning webinar	Local
18th October 2017	Learning event 2	London

18th October 2017 – 25th January 2017	***100 day action period for rapid improvement***	***Local***

9. Evaluation:

Each team will also be expected to undertake a short internal project report to document their work. This will be based on the Squire guidelines[9] and this will be provided at the beginning of the programme to successful applicants.

10. How to apply

The application form will be live on the Point of Care Foundation's website on the 24th of February 2017. For some guidance in what the application form will be asking, please see the 2016 form. Please note that this application form will be subject to revision before being launched formally on the 24th February.
If you would like an informal discussion about the programme, please get in touch with Sophie Lansdowne, Senior Programmes Officer: Quality Improvement, at the Point of Care Foundation:
T: 0203 841 5581
E: sophielansdowne@pointofcarefoundation.org.uk
Please note that the deadline for applications is 31st March 2017. For further information, please see the FAQS below.

11. Frequently Asked Questions:

What do we mean by patients' experience?

Patients' experience includes all aspects of the quality of care, as experienced by patients. The Institute of Medicine's (IoM 2001) definition of quality provides a useful definition of quality namely care that is:

- patient-centred
- safe
- effective (therefore encapsulating clinical quality)
- timely
- efficient
- equitable

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[9] Davidoff F et al. (2008) Publication guidelines for quality improvement in health care: evolution of the SQUIRE project. *Quality and Safety in Healthcare* 17 (Suppl.1)

The IoM further goes on to define the dimensions of patient-centred care as demonstrating all of the following attributes:

- compassion, empathy and responsiveness to needs, values and expressed preferences
- co-ordination and integration
- high-quality information, communication and education
- delivering physical comfort
- providing emotional support, relieving fear and anxiety
- involving family and friends

This definition goes beyond single aspects of patient-centred care, such as dignity. It is distinct from concepts, such as patient involvement, in planning and delivery of services more broadly.

What do we mean by a care experience?

This programme focuses on improving the end of life 'care experience' for patients. By care experience we mean an aspect of care that is defined from the patients' perspective. You will decide where to focus your work – for example on particular wards or teams, and when the experience begins and ends. For example, the experience might begin when patients are admitted to a particular setting. It might continue as patients move between settings; and might end with the follow-up and bereavement care of families after the death of a loved one.

What is the role of the executive sponsor?

There are two aspects to the role of the executive sponsor – first to demonstrate organisational leadership for work on patients' experience, and second to hold project teams to account.

The leadership role comprises:

- demonstrating that the organisation values patient-centred care, and that patients' experience is core business
- advocating organisational values that place patients' experience at the core
- supporting practical steps to reward patient-centred care
- modelling the priority and importance of the work, through regularly attending steering groups, noticing and taking an interest in the data emerging from the work, etc.
- showing energy and enthusiasm – challenging cynicism
- identifying the resources necessary to conduct the work, negotiating across the organisation where changes/improvements have repercussions that go beyond the clinical area that is under detailed review (e.g., identifying blockages that are preventing improvements from happening or being sustained)
- ensuring that there is time allocated for participants to do this work

- ensuring the programme is reinforced as a learning programme as well as an improvement programme.

The accountability role comprises:

- holding the core team and project teams to account
- ensuring there is administrative support/a scribe to keep track of the work
- ensuring that the work is reported regularly to the board, and that there is commitment to action in response to these reports.

In practical terms this will mean that the executive sponsor will:

- link the work of the programme into the organisation's broader vision, values and objectives – and will not allow it to be conducted in isolation
- ensure that the work draws in corporate services, such as HR or facilities, where this is needed to advance the work of the programme
- engage Board colleagues in the work, to ensure the Board pays attention to the PFCC work and it is celebrated in the organisation
- chair the Guiding Council for the PFCC programme and attend the meetings regularly. This role is described as 'a committed, enthusiastic, and organised professional to serve as a champion to guide and expand the PFCC work and to serve as the linchpin for communications'. This group should aim to meet every fortnight for 30 minutes – same place, same time.
- ensure that invitations for sub-groups are sent from the sponsor's own office, giving a clear message that this work is valued at a senior level in the organisation, and that active participation is strongly encouraged
- lead by example, participating in aspects of the programme

What is the role of the clinical champion?

The clinical champion is similar to the executive sponsor: they provide clinical leadership to this work and are an active member of the Guiding Council, and provide support to the Core or Working Group.

The clinical champion will inspire colleagues to make and sustain required changes. Key aspects of the role include:

- being a member of the Guiding Council for the PFCC programme, and attending the meetings reliably. Like the executive sponsor, 'a committed, enthusiastic, and organised professional to serve as a champion to guide and expand the PFCC work.' This group should aim to meet every fortnight for 30 minutes – same place, same time
- modelling the priority and importance of the work, through regularly attending steering groups, noticing and taking an interest in the data emerging from the work, etc.
- showing energy and enthusiasm, and challenging cynicism

- negotiating across the organisation where changes/improvements have repercussions that go beyond the clinical area that is under detailed review
- lead by example – including participating in project groups and patient shadowing.

What is the role of the key contact?
The key contact is the main point of contact between the Point of Care Foundation team, the faculty and the trust. Typically this person is a senior member of staff with expertise in improvement, who is well connected in the organisation. The key contact:

- acts as a conduit for communications between The Point of Care Foundation team, faculty and the teams
- is a source of support and expertise regarding the programme for the participating teams
- cascades information sent by the Point of Care foundation team to relevant team members and ensure that teams have committed to action when needed
- will be the point of co-ordination for feedback to the Point of Care Foundation team in relation to:
  - providing routine reports and feedback to The Point of Care Foundation and senior management within the trust
  - having regular catch-up calls with team and faculty
  - ensuring that teams collect data on agreed measures
  - ensuring that the teams keep to their agreed project plans
  - maintaining momentum – ensuring that teams hold relevant local events etc
  - co-ordination of requests for help and support from teams to The Point of Care Foundation team and faculty.

Key contacts:

- are not a substitute for the teams themselves
- will not necessarily know the details of the work, and will rely on the core team to provide this information.

Who should form the core team?
The core team will typically comprise 6 individuals, and include a senior nurse, doctor and manager. (For smaller organisations, such as those within primary care, we will discuss the team composition with you). It is vital that staff who work directly with patients are involved in the programme.

The core team must have the time, resource and support from within their organisation to carry out this work effectively. Typically, this might represent a half day per week, but it will depend on the scale of the work undertaken, the complexity of the pathway, and the extent to which you broaden the work out to include more frontline staff.

You yourselves will know who it is in your organisation that is likely to make change happen. This is far more important than the specific professional background of the individuals.

Additional frontline staff will participate in local learning events as well as small, time-limited projects, identified by the core team. The extent of this will depend on the complexity of the work undertaken by the teams.

About the Point of Care Foundation:

We are an independent charity working to radically improve the way people are cared for and to support the staff who deliver care. The Patient and Family Centred Care programme was previously run by the Point of Care team at the King's Fund, supported by the Health Foundation.

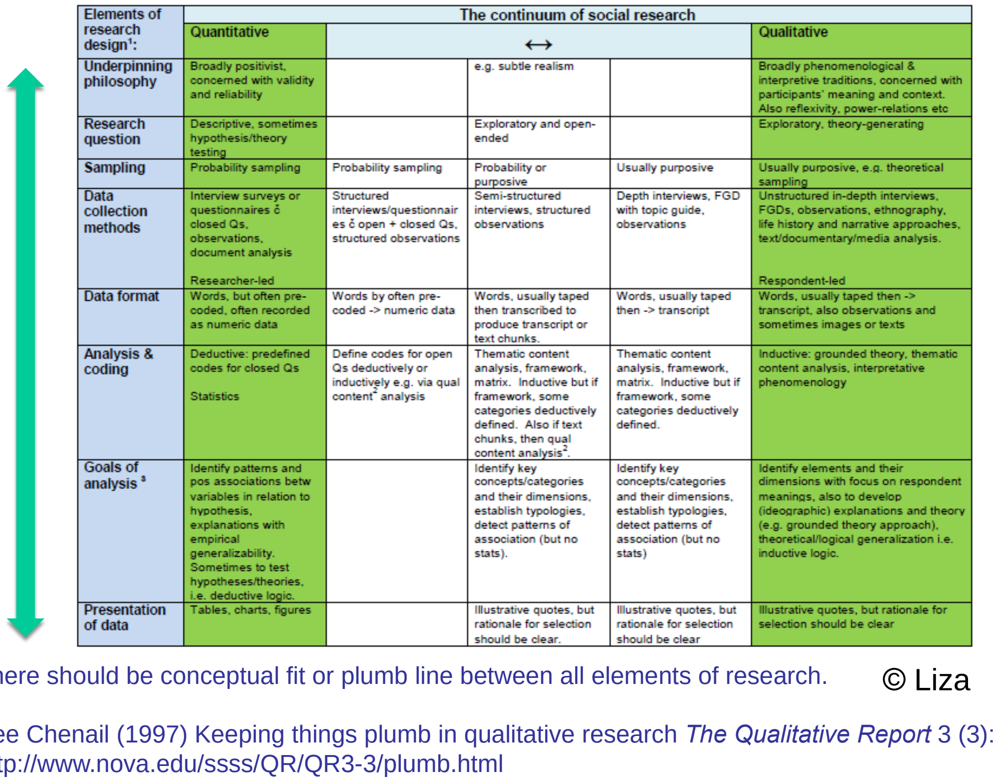
About The Health Foundation

Patient and family centred care is part of The Health Foundation's spreading improvement programme. The Health Foundation is an independent charity working to continuously improve the quality of health care in the UK.

Additional resources about the programme methods

- The Patient and Family Centred Care 'Go Guide'
- The Patient and Family Centred Care toolkit

Appendix C: Continuum of social research (lecture handout). Draper, 2017.



Elements of research design[1]:	The continuum of social research			
	Quantitative	↔		Qualitative
Underpinning philosophy	Broadly positivist, concerned with validity and reliability		e.g. subtle realism		Broadly phenomenological & interpretive traditions, concerned with participants' meaning and context. Also reflexivity, power-relations etc
Research question	Descriptive, sometimes hypothesis/theory testing		Exploratory and open-ended		Exploratory, theory-generating
Sampling	Probability sampling	Probability sampling	Probability or purposive	Usually purposive	Usually purposive, e.g. theoretical sampling
Data collection methods	Interview surveys or questionnaires č closed Qs, observations, document analysis Researcher-led	Structured interviews/questionnaires č open + closed Qs, structured observations	Semi-structured interviews, structured observations	Depth interviews, FGD with topic guide, observations	Unstructured in-depth interviews, FGDs, observations, ethnography, life history and narrative approaches, text/documentary/media analysis. Respondent-led
Data format	Words, but often pre-coded, often recorded as numeric data	Words by often pre-coded -> numeric data	Words, usually taped then transcribed to produce transcript or text chunks.	Words, usually taped then -> transcript	Words, usually taped then -> transcript, also observations and sometimes images or texts
Analysis & coding	Deductive: predefined codes for closed Qs Statistics	Define codes for open Qs deductively or inductively e.g. via qual content[2] analysis	Thematic content analysis, framework, matrix. Inductive but if framework, some categories deductively defined. Also if text chunks, then qual content analysis[2].	Thematic content analysis, framework, matrix. Inductive but if framework, some categories deductively defined.	Inductive: grounded theory, thematic content analysis, interpretative phenomenology
Goals of analysis [3]	Identify patterns and pos associations betw variables in relation to hypothesis, explanations with empirical generalizability. Sometimes to test hypotheses/theories, i.e. deductive logic.		Identify key concepts/categories and their dimensions, establish typologies, detect patterns of association (but no stats).	Identify key concepts/categories and their dimensions, establish typologies, detect patterns of association (but no stats)	Identify elements and their dimensions with focus on respondent meanings, also to develop (ideographic) explanations and theory (e.g. grounded theory approach), theoretical/logical generalization i.e. inductive logic.
Presentation of data	Tables, charts, figures		Illustrative quotes, but rationale for selection should be clear.	Illustrative quotes, but rationale for selection should be clear	Illustrative quotes, but rationale for selection should be clear

There should be conceptual fit or plumb line between all elements of research.

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See Chenail (1997) Keeping things plumb in qualitative research *The Qualitative Report* 3 (3): http://www.nova.edu/ssss/QR/QR3-3/plumb.html

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Appendix D: Questionnaires for 'Living Well' programme participants (pre-and post-shadowing)

Pre-shadowing

1. About you:

a) What is your professional background (please tick)

clinical ☐ please state……………….
non-clinical ☐ please state……………….
Other ☐ please state……………….

b) How long have you worked in health care? (please tick)

Less than 5 years ☐
5-10 years ☐
10-20 years ☐
20-30 years ☐
more than 30 years ☐

2. Please rate your knowledge and understanding of patient shadowing as an improvement method (please circle, where 1 is very little to very good)

1 2 3 4 5

3.Please rate how confident you feel about patient shadowing as an improvement method (please circle where 1 is not at all confident to 5 is very confident)

1 2 3 4 5

4.How confident are you that you know what the experience of patients is like (in your service)? (please circle where 1 is not at all confident to 5 is very confident)

1 2 3 4 5

Please comment on why you gave this answer…………………………..

PTO

5.How confident are you that you know what the experience of their family is like (in your service)? (please circle where 1 is not at all confident to 5 is very confident)

1 2 3 4 5

Please comment on why you gave this answer……………………………….

6. To what extent do you agree or disagree with the following statements?

	Strongly disagree	*Slightly disagree*	*Slightly agree*	*Strongly agree*
a. I am good at predicting how a patient will feel				
b. I am quick to spot when a patient is feeling awkward or uncomfortable				
c. I can sense if I am intruding, even if the patient does not tell me				
d. I can tune in to how a patient feels rapidly and intuitively				
e. I can easily work out what a patient might want to talk about				

7. How are you feeling about shadowing patients. Please circle one or more of these words:

confident excited sceptical nervous awkward interested

and/or please add your own words……………………………………………………………………………………………….

Please provide your surname (the data will be anonymised) ……………………………..

Male/female (please circle)

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Post-shadowing

1. About you:

a) What is your professional background (please tick)

clinical	☐	please state………………..
non-clinical	☐	please state……………….
Other	☐	please state……………….

b) How long have you worked in health care? (please tick)

Less than 5 years	☐
5-10 years	☐
10-20 years	☐
20-30 years	☐
more than 30 years	☐

2. Please rate your knowledge and understanding of patient shadowing as an improvement method (please circle, where 1 is very little to very good)

1 2 3 4 5

3.Please rate how confident you feel about patient shadowing as an improvement method (please circle where 1 is not at all confident to 5 is very confident)

1 2 3 4 5

4.How confident are you that you know what the experience of patients is like (in your service)? (please circle where 1 is not at all confident to 5 is very confident)

1 2 3 4 5

Please comment on why you gave this answer……………………………

5.How confident are you that you know what the experience of their family is like (in your service)? (please circle where 1 is not at all confident to 5 is very confident)

1 2 3 4 5

Please comment on why you gave this answer……………………………….

6. To what extent do you agree or disagree with the following statements?

	Strongly disagree	*Slightly disagree*	*Slightly agree*	*Strongly agree*
a. I am good at predicting how a patient will feel				
b. I am quick to spot when a patient is feeling awkward or uncomfortable				
c. I can sense if I am intruding, even if the patient does not tell me				
d. I can tune in to how a patient feels rapidly and intuitively				
e. I can easily work out what a patient might want to talk about				

7. Did you shadow a patient or patients as part of your PFCC project?

Yes/No (please circle)

If, no, please could you say why this was? ……………………………………………………..

If yes, how do you feel about shadowing now? Please circle one or more of these words:

confident sceptical awkward

and/or please add your own words ……………………………………………………………………………………………………

Please provide your surname (the data will be anonymised) ……………………………..

Male/female (please circle)

MANY THANKS

Appendix E: Ethics approval

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Dear Joanna

I am writing to inform you that your application was considered by the FST Research Ethics Committee at its meeting of 29 Jun 2017.

The proposal was approved with the following conditions:
* A letter of permission must be obtained from the foundation organising events at which the research will take place.

* All complaints, major or minor, should be addressed to the project supervisor in the first instance; this must be clarified in the Participant Information Sheet.

* It should also be stated in the Participant Information Sheet that the project will be approved by the Faculty Research Ethics Committee, and not the University Research Ethics Committee.

If these conditions are met, the application does not need to be returned to the Committee for further consideration. Yours,
Mandy Walton
FST Research Ethics Committee

I am advised by the Committee to remind you of the following points:

Your responsibility to notify the Research Ethics Committee immediately of any information received by you, or of which you become aware, which would cast doubt upon, or alter, any information contained in the original application, or a later amendment, submitted to the Research Ethics Committee and/or which would raise questions about the safety and/or continued conduct of the research.

The need to comply with the Data Protection Act 1998.
The need to comply, throughout the conduct of the study, with good research practice standards.

The need to refer proposed amendments to the protocol to the Research Ethics Committee for further review and to obtain Research Ethics Committee approval thereto prior to implementation (except only in cases of emergency when the welfare of the subject is paramount).

The desirability of including full details of the consent form in an appendix to your research, and of addressing specifically ethical issues in your methodological discussion.

The requirement to furnish the Research Ethics Committee with details of the conclusion and outcome of the project, and to inform the Research Ethics Committee should the research be discontinued. The Committee would prefer a concise summary of the conclusion and outcome of the project, which would fit no more than one side of A4 paper, please.

Appendix F: Participant information sheets and consent form

UNIVERSITY OF
WESTMINSTER

Participant information sheet (Qualitative interviews)

‘Through the patient’s eyes’: an exploratory evaluation study of the impact on healthcare staff of a quality improvement method which helps them to understand the experience of their patients.

You are being invited to take part in a research study as part of a postgraduate research project contributing to a Professional Doctorate in Health Sciences at The University of Westminster. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Who will conduct the research?

Joanna Goodrich
Prof Doc Research Student
The University of Westminster
115 New Cavendish Street
London
W1W 6UW

What is the purpose of the research?

The Point of Care Foundation’s Patient and Family Centred Care programme has run three times with clinical teams from around England. Teams have reported that one of the features of the programme, shadowing their patients and families, was key to the success of their project. They have reported that in some cases it made quite a dramatic impact on them and their work. This research project aims to improve our understanding of why this is. Managers in the NHS need research evidence to make decisions about where best to invest resources, and we hope this research project will make the case for this approach to quality improvement. The research will also look at the practical challenges involved in shadowing and what teams have learned so far to contribute to a Guide for future teams to use.

Why have I been invited to take part?

You have been invited to participate in this study because you are taking part in the Point of Care Foundation’s Patient and Family Centred Care programme. By understanding what taking part in the programme is like for you, particularly shadowing your patients and their families, we hope to be able to help others in the future use this approach to improve the quality of care in the health service where they work [and write a guide] We hope to conduct 20 - 30 interviews during this research.

Do I have to take part?

Participation in this research is entirely voluntary. We are very grateful for the time that you spend on it.

What would I be asked to do if I participate?

If you agree to take part in this study, we will ask you to take part in an individual interview with the researcher. The interview will usually take about an hour. We will ask your permission to audio-record the interview and to take notes, so that we can keep an accurate record of what you say. We will summarise what you say and combine your comments with those of other participants. We may use direct quotations from your interview which will be reported anonymously.

Where will the research be conducted?

The interview would take place at a time and place convenient to you. If it is not practical to arrange a face to face interview, then we will offer the option of a telephone interview, or a skype interview, again at a time convenient to you. The cost of the telephone call would be covered by the researcher.

What happens to the data collected and how will you maintain my confidentiality?

If you agree to your interview being audio-recorded, it will be recorded on a digital recorder with an anonymous identifier. It will be downloaded onto an electronic database and transcribed verbatim, following which the recording will be destroyed. The transcript will be assigned an anonymous identifier, so that only the researcher will be able to tell which interview is yours. Notes taken during the interview will be kept using an anonymous identifier. The transcript data and notes will be kept securely at the University of Westminster for a period of 5 years, and subsequently destroyed.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You will still be free to withdraw at any point, without giving a reason.

How will I find out the results of the research?

You will be offered the opportunity to receive a brief, written summary of the research findings, following submission of the ProfDoc thesis. This is entirely voluntary.

Will the outcomes of the research be published?

The outcomes of this research will form the basis of a Guide on shadowing for future teams undertaking quality improvement projects, and may be presented at conferences, and as a short report on The Point of Care Foundation's website. The research will be submitted as Joanna Goodrich's ProfDoc thesis and may be submitted for publication in peer reviewed journals.

Who has reviewed the research project?

The research project has been reviewed and approved by Faculty Research Ethics Committee, The University of Westminster.

What if something goes wrong?

If, for any reason, you wish to withdraw from the study either before or during the interview, you are free to do so without giving a reason and without detriment to yourself. If, for any reason, you become uncomfortable during the interview, the interview will be paused and you will be given time to consider whether you wish to carry on or withdraw. If you wish to withdraw any comments from the interview, this data can be deleted without giving a reason and without detriment to yourself. After the interview, you are free to withdraw until [date], at which point the findings will be submitted as part of the thesis for ProfDoc qualification, without giving a reason and without detriment to yourself.

If you require help or advice following the interview, please contact Joanna Goodrich (details below).

What if I want to make a complaint?

Complaints

If you have any complaint then you may contact the researcher's supervisor in the first instance:

Dr Tina Cartwright
The University of Westminster
115 New Cavendish Street
London W1W 6UW
Telephone 0207 911 5000
Email**:** T.Cartwright@westminster.ac.uk

What Do I Do Now?

If you have any queries about the study or if you are interested in taking part then please contact the researcher:

Joanna Goodrich
Prof Doc Research Student
The University of Westminster
115 New Cavendish Street
London W1W 6UW
Telephone 0207 911 5000
Email w1614740@my.westminster.ac.uk

This Project Has Been Approved by the Faculty Research Ethics Committee, University of Westminster, approval reference: ETH1617-1486

CONSENT FORM

‘Through the patient’s eyes’: an exploratory evaluation study of the impact on healthcare staff of a quality improvement method which helps them to understand the experience of their patients.

If you are happy to participate, please complete and sign the consent form below.

Please initial box

1.	I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2.	I understand that my participation in the study is voluntary and that I am free to withdraw at any time until [date] without giving a reason and without detriment to my participation in the PFCC programe	
3.	I understand that my data will remain confidential.	
4.	I understand that the interviews will be audio-recorded.	
5.	I agree to the use of anonymous quotes.	
6.	I agree that any data collected may be archived, and used as anonymous data in research	

I agree to take part in the above project

Name of participant	Date	Signature
Name of researcher	Date	Signature

This Project Has Been Approved by the Faculty Research Ethics Committee, University of Westminster, approval reference: ETH1617-148

Participant information sheet (Survey)

RESEARCH INTO SHADOWING

‘Through the patient’s eyes’: an exploratory evaluation study of the impact on healthcare staff of a quality improvement method which helps them to understand the experience of their patients.

You are being invited to take part in a research study at The University of Westminster. It is important for you to understand why the research is being done and what it will involve.

What is the purpose of the research?

The Point of Care Foundation’s Patient and Family Centred Care (PFCC) programme has run three times with clinical teams from around England. Teams have reported that one of the features of the programme, shadowing their patients and families, was key to the success of their project. They have reported that in some cases it made quite a dramatic impact on them and their work. This research project aims to improve our understanding of why this is.

Clinicians in the NHS need research evidence to demonstrate whether shadowing is a valid, evidence-based improvement method and this research project seeks to address this question.

The research will also look at the practical challenges involved in shadowing and what teams have learned so far.

By understanding what taking part in the programme is like for you, particularly shadowing your patients and their families, we hope to be able to help others in the future use this approach to improve the quality of care in the health service where they work. We want to write a Shadowing Guide which is realistic about any anxiety and concerns beforehand, and about the practical experiences and what contributes to the success of shadowing.

Why have I been selected to take part?

You have been invited to participate in this study because you have taken part in the Point of Care Foundation’s Patient and Family Centred Care programme. By understanding what taking part in the programme was like for you, particularly shadowing your patients and their families, we hope to be able to help others in the future use this approach to improve the quality of care in the health service where they work. We plan to write a Shadowing Guide for future teams. Everyone on the PFCC programme received a questionnaire at the first Learning Event and again at the last Learning Event. We also hope to conduct 20 - 25 interviews during this research about the process and experience of shadowing.

Do I have to take part?

Participation in this research is entirely voluntary.

What am I being asked to do?

We are asking you to complete this short questionnaire now

What happens to the data collected and how will you maintain my confidentiality?

Your answers will be anonymous. Although your name will be on the questionnaire it will be seen only by the researcher. It will be linked to a number (an anonymous identifier) and as soon as the questionnaire data are collected, your name will be deleted from all records. The data will be kept securely for a period of five years, and subsequently destroyed.

Will the outcomes of the research be published?

The outcomes of this research will form the basis of the Shadowing Guide and may be presented at conferences, and as a short report on The Point of Care Foundation's website, and may be submitted for publication in peer reviewed journals.

What if I want to make a complaint?

For all complaints, you can contact the researcher's supervisor in the first instance:

Dr Tina Cartwright
The University of Westminster
115 New Cavendish Street
London W1W 6UW
Telephone 020 7911 5000
Email**:** T.Cartwright@westminster.ac.uk

This Project Has Been Approved by the Faculty Research Ethics Committee, University of Westminster, approval reference: ETH1617-1486

Appendix G: Revised semi-structured interview schedule (January 2018)

1.Can you tell me a bit about yourself?

(what is your role….clinical/patient-facing or not…..how long have you worked where you are now….in the NHS)

Can you tell me how you came to do the shadowing?

2. Can you tell me about your experience of shadowing?

(First time? Where......more than one setting?... when.....who.....how much?)

Ask for description of environment

3. How easy was it to arrange?

4. How did you feel about it beforehand?

5. And how did it go? (*Did staff/patients/family know why you were there*)

6. How did you feel while you were shadowing? (*probe for having to step out, emotions felt etc*)

7. How do you think the patient/family felt?

8. Thinking about it now, has it changed what you know about patient's/family's experience (*probe for both process and relational issues*) .

How did you feed back to the team? Did you use a structured framework/make notes?

9. How much do you think you or others get to understand and empathise with patients'/families' experiences doing this?

9.Thinking about empathy– and empathic care –how would you describe that?

Do you think it can be learned (probe for any other types of training etc)

Would you say shadowing made a difference to your levels of empathy? (How much empathy you usually feel for patients and families…..before/after shadowing)

10.What does empathetic care mean to you (*probe for examples in them or colleagues, training received, patient themselves, family member*)

11.Has it helped identify improvements you would like to make? (give specific examples)

12. [*If yes*] How do you think it helped [*probe whether due to change in knowledge/emotional response*]

13. [*If no*] Why do you think that is?

14. What do you think about shadowing as part of a quality improvement programme?

And do you think it's appropriate in end of life care? (probe for ethics etc)

15. Would you recommend it to others?

16. Has it made you more or less enthusiastic about the whole programme?

17. Do you think your professional background made you see things in a certain way? /could you put it aside?

Did you see anything you didn't know about /surprised you?

Has it made any difference to how you feel about your work?

18.Has it made any difference to the way you might act/behave at work?

19.Have you got any advice or tips for others doing shadowing in the future? (*probe for differences between clinical and non-clinical staff)*

20. Can you suggest any other people I should interview?

First draft interview schedule, June 2017

1. Can you tell me about your experiences of shadowing
2. How much shadowing did you manage to do
3. Where……when…..who…..?
4. How easy was it to arrange?
5. How did you feel about it beforehand?
6. And how did it go?
7. How did you feel while you were shadowing?
8. How do you think the patient/family felt?
9. Thinking about it now, has it changed what you know about patient's /family's experience (probe for both process and relational issues)
10. How do you think you relate to patients'/families' experiences?
11. Do you think the shadowing has changed this at all?
12. Thinking about the concept of empathy – what does this mean to you? [probe for at work/ in a wider sense]
13. Did the shadowing make a difference to how much empathy you might feel for patients and their families?
14. Has shadowing helped identify improvements you would like to make? (probe for specific examples)
15. [if yes]How do you think it helped [probe whether due to change in knowledge/emotional response]
16. [if no] why do you think that is?
17. What do you think about shadowing as part of a quality improvement programme?
18. Would you recommend it to others?
19. Has it made you more or less enthusiastic about the programme?
20. Has it made any difference to how you feel about your work?
21. Has it made any difference to the way you might act/behave at work?
22. Have you got any advice or tips for others doing shadowing in the future?

Appendix H: Improvements to patient-centred care documented by teams represented in the study

Hospital team 1

- Increased use of Priorities of Care Individualised Care plans for patients in last days of life
- Improved development of individualised advanced care plans for patients discharged home
- Lockdown lunch where all staff including managers comes to the ward to help patients eat
- Open visiting times to enable visitors to care for loved ones
- Increased drive to recruit more volunteers to help with emotional support and activities, and 'adopt a grandparent' scheme
- Safety Huddle introduced to improve communication within MDT regarding challenges of that day

Hospital team 2

- Musicians invited to wards to improve the boredom and environment
- Work to improve information board on wards to improve communication between MDT
- Employed a new role on the wards to reduce complex discharge delays
- Use of blue plates as proven to encourage eating and thus improve nutrition

Hospital team 3

- Purple Butterfly sign for room door to highlight to staff that a patient was nearing end of life
- Purple Butterfly symbol on electronic flow board to highlight to bed managers and other professionals that there were dying patients on the ward
- Purple Butterfly sticker on drug charts to that pharmacists prompted to check ward drug stocks and charts processed quickly through pharmacy

- “Tell us about you” form to encourage staff to ask patients about personal things that are important to them in advance care planning
- New symptom chart so that patients are asked a number of patient-centred questions
- Delivery of ward based training for staff and half day communication skills workshops to improve confidence in having conversations about end of life care
- Development of ‘after death huddle’ at each shift handover to talk about what happened, what went well and what could have been improved

Hospital team 4

- Call bells in reach
- In collaboration with catering team, small meals offered
- New beds for family to stay
- Bedsides decluttered
- Designated parking for relatives visiting patients near end of life
- Provision of food for relatives, and a quiet room

Clinical Commissioning Group

- ‘Red bag’ initiative for care homes, with all necessary information and paperwork for advance care planning, with training rolled out across CCG.
- General communication training being rolled out across CCG
- Care home bedrooms refurbished

Appendix J: Dissemination Activities

Peer reviewed paper: Goodrich, J., Ridge, D. and Cartwright T. (2020). “As soon as you’ve been there it makes it personal”: the experience of healthcare staff shadowing patients at the end of life. *Health Expectations,* 2020;00:1–10. https://doi. org/10.1111/hex.13107

Oral conference presentation: Goodrich, J., Ridge, D. and Cartwright, T. (2020) "It was a real eye-opener": shadowing patients at the end of life to improve their experience of care. Health Services Research UK conference. Manchester, July 2020. [Held online due to Covid-19 pandemic].

Conference poster presentation: Goodrich J., Fitzsimons, B., Ridge, D. and Cartwright, T. "Through the patient's eyes": shadowing patients at end of life as an approach to improve person and family centred care. IHI/BMJ International conference. Copenhagen, April 2020. [Conference postponed due to Covid-19 pandemic].

Oral conference presentation: Goodrich, J. (2019) Shadowing patients at the end of life. Hospice UK conference, ‘Dying for Change’. Liverpool, November 2019.

Oral presentation: Goodrich, J., Ridge, D. and Cartwright, T. “Through the patient’s eyes”: the experience of shadowing patients at the end of life. University of Westminster Psychology Research Forum. London, June 2019.

Oral presentation: Goodrich, J., Ridge, D. and Cartwright, T. How does shadowing their own patients impact on healthcare staff’s knowledge, motivation and empathy? University of Westminster FSR doctoral conference. London, April 2018.

Guidance for professionals:

Shadowing chapter in The Point of Care Foundation's Sweeney Programme handbook (2020)

'What the research tells us: practical tips for shadowers' written for 2019 Sweeney programme, End of Life care collaborative.

Online shadowing module recorded for Sweeney Programme (for use during social distancing due to Covid-19, May 2020).

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